UNIVERSITY OF ALBERTA

Informal Caregiving Experience and Meaning

Home-Based Palliative Cancer Care

by

Tasnim Hirani

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of *Master of Nursing*

Faculty of Nursing

Edmonton, Alberta

Fall 2003

National Library of Canada
Acquisitions and Bibliographic Services
395 Wellington Street
Ottawa ON K1A 0N4
Canada

Bibliothèque nationale du Canada
Acquisisitons et services bibliographiques
395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file Votre référence
ISBN: 0-612-87615-2
Our file Notre référence
ISBN: 0-612-87615-2

The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.

The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.

L'auteur conserve la propriété du droit d'auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou aturement reproduits sans son autorisation.

Canada

UNIVERSITY OF ALBERTA

Library Release Form

Name of Author: *Tasnim Hirani*

Title of Thesis: *Informal Caregiving Experience and Meaning Home-Based Palliative Cancer Care*

Degree: *Master of Nursing*

Year this Degree Granted: *2003*

Permission is hereby granted to the University of Alberta to reproduce single copies of this thesis and to lend or sell such copies for private, scholarly or scientific research purposes only.

The author reserves all other publication and other rights in association with the copyright in the thesis, and except as herein before provided, neither the thesis nor any substantial portion thereof may be printed or otherwise reproduced in any material form whatever without the author's prior written permission.

22 SEPT 2003

UNIVERSITY OF ALBERTA

Faculty of Graduate Studies and Research

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled *Caregiving Experience and Meaning* submitted by *Tasnim Hirani* in partial fulfillment of the requirements for the degree of *Master of Nursing*.

Dr. V. Strang

Dr. P. Koop

Dr. M. Haughey

Aug 27/03

ABSTRACT

The purpose of this study was to describe and interpret the informal caregiving experience and meaning during home-based palliative care for persons with advanced cancer. This secondary analysis used the interpretive approach. The 15 informal caregivers of the original study provided 29 interviews that were transcribed verbatim. Thematic data analysis followed the hermeneutic spiral. The caregiving context was described as a critical, intense, enclosed time. Love was the all encompassing theme in the caregiving experience. Within this theme a movement from the themes of suffering to transformation was evident. Meaning in caregiving was embedded within the love theme, the search for meaning was prompted in suffering, and transformation occurred through reflection on the experience. Both positive and negative dimensions coexisted within the caregiving experience. Increased awareness of the informal caregiving experience and meaning will enable health professionals to participate deeply in caregiving and be present to the caregivers and their loved ones.

Meaning is the essence of experience

DEDICATION

This thesis is dedicated to the friend and my parents

ACKNOWLEDGEMENT

I would like to acknowledge my family, friends, professors, students and colleagues for their support in thoughts, words, and actions.

I appreciate the informal caregivers for sharing their caregiving experience; in their sharing they provided me with the opportunity to learn.

Thank you to everyone.

TABLE OF CONTENTS

I. INTRODUCTION 1

Purpose 3

Format 4

II. LITERATURE 5

Terminal Cancer 5

Caregiving 6

Experiential Literature 7

Experience of Caregiving 7

Meaning in Caregiving 12

Summary 15

III. METHOD 16

Secondary Analysis 16

Primary Research 18

Secondary Research 19

Research Orientation 21

Data Management 25

Data Analysis 26

Preunderstanding 27

Context 27

Technique 28

Outcome 29

Illustration 30

Rigour 35

Credibility 35

Auditability 36

Ethics 36

IV. FINDING AND DISCUSSION 38

Preunderstanding 38

Reflections from a Personal Perspective 39

Reflections from a Professional Perspective 40

Summary of Reflections and Expectations 41

Demographic Data 42

Caregiver Profile 44

Themes and Interpretation 63

Caregiving Context 63

Caregiver Involvement 64

Perception of Space 64

Perception of Time 65

Discussion on the Caregiving Context 66

Caregiving Experience 67

Love 68

Connection. 70

Togetherness. 71

Caring. 72

Commitment. 73

Communication. 74

Respect and admiration. 74

Discussion on Love. 75

Suffering 81

Watching. 83

Living. 84

Memories. 85

Discussion on Suffering 86

Transformation 90

Self discovery. 92

Interpersonal relation. 93

Thought and perception. 93

Discussion on Transformation 94

Caregiving Meaning 99

Relationship to Caregiving Literature 106

Reflection 116

V. IMPLICATION AND CONCLUSION 118

Summary 118

Practice Implication 123

Research Implication 127

Limitation 129

Conclusion 130

REFERENCE 131

APPENDIX A: Primary Study: Ethics Approval 146

APPENDIX B: Primary Study: Consent Form 148

APPENDIX C: Primary study: Interview Guide 152

APPENDIX D: Secondary Study: Ethics Approval 154

APPENDIX E: Secondary Study: Agreement Contract 155

LIST OF TABLES

Table 1: Experiential Literature 9

Table 2: Caregiver Demographic 43

LIST OF FIGURES

Figure 1: Hermeneutic Spiral or Circle 34

Figure 2: Caregiving Experience and Meaning 101

INTRODUCTION

The global incidence of cancer is increasing; by 2020 there will be over 15 million new cases per year (World Health Organisation, 2003). Analysts estimate that between 2000 and 2015, the number of new cancer cases in Canada will grow by 70% (National Cancer Institute of Canada, 2000). This increase is related to the growth in the size and age of the Canadian population (National Cancer Institute of Canada, 1997). According to the National Cancer Institute of Canada (2003), 80% of cancer deaths and 69% of new cancer cases occur among those who are aged sixty and above.

Increasing costs of health care, tightening resource allocations, and policy changes have resulted in major changes in the Canadian health care system during the last 20 years. These changes have included plans that emphasise alternatives to institutional care including the provision of more community-based services such as home care. Studies have suggested that community-based care can be a cost-effective alternative to hospital or long-term residential care for patients; however, little is known about the impact of these changes on the life of patients, caregivers, families, or friends (Canadian Institute for Health Information, 2000).

Cancer patients require palliative care during the terminal stage of illness. According to the World Health Organisation (1990), palliative care or end-of-life care is the active total care of patients whose disease is not responsive to curative treatment. The aims of palliative care are relief of distressing symptoms, integration of psychological and spiritual aspects of care, and the provision of a support system for families during the illness and bereavement. Palliative care is

provided in various settings such as hospitals, nursing homes, hospices, and at home, and relies on both formal (health professionals/para-professionals) and informal/lay caregivers/carers (families/friends). Home-based palliative care is increasing due to the changes in the Canadian health care system. Informal caregivers are therefore, assuming more caregiving responsibilities, which in turn has a significant impact on their lives (Lev & McCorkle, 1998).

Research on the terminal phase of cancer is extensive. Most of the early studies were from the perspective of the patient, while more recent literature is based on the informal caregiver perspective. A number of studies describe the experience of informal caregivers of terminally ill cancer patients during home-based palliative cancer care. However, only a few studies were found that were from an interpretive orientation describing the meanings of the caregiving experience for the informal caregivers. Health professionals, especially palliative care nurses working with terminal cancer patients and their caregivers, need to appreciate the home-based palliative cancer caregiving experience of informal caregivers in order to work effectively with them. Therefore, this study will describe and interpret the subjective caregiving experience of informal caregivers who provided home-based palliative cancer care to their loved ones. The present study will also explore the meanings caregivers ascribed to their experience.

Purpose

The purpose of this study is to describe and interpret the informal caregiving experience and the meanings in it in order to increase the health professionals' awareness and understanding of it. Insight into the informal caregiving experience and meanings will enable the health professionals to provide realistic, appropriate, respectful, sensitive, and supportive care to the terminal cancer patients and their informal caregivers. An understanding of the informal caregiving experience and meanings will allow the health professionals to foster environments that promote mutual exchange of knowledge, expertise, and values; and facilitate an equal partnership in providing care to the terminally ill. A profound awareness of the informal caregiving experience and meanings will also enable the health professionals to personalise their care to the patients and the informal caregivers.

The caregiving period has been conceptualised as a transitional period for the caregiver (Seltzer & Li, 1996, 2000). Such transitional periods have a potential for being stressful. Research has shown that informal caregivers undergo significant changes during this time due to the process of personal management and achieve personal growth. An appreciation of the perspectives of the informal caregivers as they go through the changes and the meanings they find in their experience will provide the health professionals with valuable knowledge and insight. This can enhance the health professionals' practice by allowing them to anticipate the journey that the informal caregivers make during terminal cancer caregiving. This knowledge and insight will also enable the health professionals

to support the informal caregivers in their work of helping their loved ones exit life peacefully and at the same time maintain their own well being.

The intent of this study is to describe and interpret the caregiving experience of the informal caregivers and the meanings they ascribe to their experience. The specific research questions are: 1) What is the caregiving experience of informal caregivers of palliative care cancer patients dying at home? 2) What meanings do the caregivers ascribe to their experience?

Format

Explanation of the terminology and the experiential literature on informal caregivers of palliative cancer patients is reviewed in chapter 2. The methodology, rigor, and ethical issues are discussed in chapter 3. The findings, interpretations, and meanings are described, discussed and related to the caregiving literature in chapter 4. The study is summarised and the research and practice implications including the limitations are provided in chapter 5.

LITERATURE

Literature on cancer care, palliative care, patient perspectives, and formal/informal caregiver perceptions during cancer is extensive. The purpose of this study is to describe and interpret the caregiving experience during home-based terminal cancer care and the meanings ascribed to this experience. Therefore, the literature review will focus on the informal caregivers' experience of providing home-based terminal cancer care to their loved ones and studies that specifically examine the notion of meaning in caregiving. The literature review will consist of an explanation of the relevant terminology and the findings from the experiential literature on informal caregivers of home-based palliative cancer patients. Literature on the meaning in caregiving will also be reviewed.

Terminal Cancer

Most research focusing on the families and informal caregivers has been conducted during the terminal stage of cancer (Northouse, 1984). Cancer patients are considered to be in the terminal stage of cancer when the diagnosis is firmly established, signs and symptoms related to progressive malignant disease are present, some prediction of the time of death is possible, and the focus of medical care is palliative rather than curative (Calman & Welsh, 1984). McCusker (1984) described terminal cancer care as that period in which there was evidence of progressive malignancy and life could not be significantly prolonged by therapy. This phase could be entered at the time of cancer diagnosis or following active treatment. Research by Vigano, Bruera and Suarez-Almazor (1999) showed that the characteristics of patients with different malignancies entering the terminal

phase were similar, consisting predominantly of loss of function, malnutrition, weakness, and a short survival period.

Caregiving

Caregiving is a complex multidimensional concept (Given, Strommel, Collins, King, & Given, 1990); and is described as a task, transition, role, or process (Bowers, 1987; Bull, 1990; Pepin, 1992). Caregiver role performance (direct care) has been defined as the "provision by a family care provider of appropriate personal and health care for a family member or significant other" (Swanson, Jensen, Specht, Johnson, & Maas, 1997, p. 68-69). Multiple informal caregiver definitions exist based on particular family relationships, living arrangements, style of care, and other factors such as caregiving description or duties (Barer & Johnson, 1990).

Caregiving has also been described as a formal/informal process (Petrick, 1991). Formal caregivers are the health professionals providing care as part of their work either in an institutional setting such as a hospital or at home. There is a purposeful relationship between the patient and the health care provider. Family and friends providing care without monetary reimbursement usually at home or in formal institutions such as the hospice are referred to as informal/lay caregivers/carers. Such informal caregivers provide assistance to their loved ones beyond the normal aid/exchange that occurs as part of everyday life.

Horowitz (as cited in Davies, 1992) described the types of services such as direct care, emotional support, financial assistance, and mediating with formal organisations and health professionals that may be provided by informal

caregivers. Kellett (1997) has stated that caregiving is a human experience; when informal caregivers describe the nature and significance of their caregiving experience, it is characterised by their personal knowledge and interpretations of themselves as caregivers. The present study will explore informal caregiving from this perspective.

Experiential Literature

This section consists of an explanation of the term 'experience' and a review of the findings from the experiential literature on informal caregivers of home-based palliative cancer patients. The term 'meaning' is explained and findings from two studies on the meaning in caregiving are also presented.

Experience of Caregiving

Experience is a process of personally observing, encountering, or undergoing something over the course of time (Webster's Dictionary, 1989). Experience is a difficult concept to describe, yet it is vital to human thought in that "to write about humans without reference to experience is like trying to think the unthinkable" (Desjarlais, 1994, p. 886). The fact that experience is rarely defined suggests that people know what it means and that it is a basic, genuine, and unchanging constant in human life. Experience has "evolved from a verb denoting an external engagement with or testing of one's surroundings to a template marking a person's subjective awareness of that engagement" (Desjarlais, 1994, p. 887).

Experience equates with a person's inner life, implies subjectivity, individuality, privacy, and is transformative in nature. Experience is related to the

unity principle of integration, coherence, and a sense of wholeness, which includes a person's thoughts, feelings, and sensations. Experience seems to be an essential part of human nature due to its defining characteristics of reflexive depth, temporal integration, and transcendental nature (Desjarlais, 1994). Watson (1991) analysed the concept of experience as used in nursing and noted that the term was used in four ways. It was used to indicate: exposure to a particular event, emotion, or situation; time spent in the nursing profession; amount of knowledge gained over time; an event, situation or emotion. In the present study the term 'experience' is used more in the sense described by Desjarlais (1994) and as an exposure to the event of caregiving as per Watson (1991).

Experiential literature on informal caregivers of cancer patients primarily utilised qualitative research methods; designs used were descriptive, grounded theory, and phenomenology. The perspectives of informal caregivers were obtained using in-depth informal interviews either during the caregiving period or within one year of the patients' death. Studies were mainly concerned with home-based informal caregiving during cancer. Each study, however, had a different approach to the situation; therefore, the focus for data collection and reporting was variable as well. Table 1 summarises the research studies in terms of the sample group and size, country, setting, interview time, cancer trajectory, and the study design.

Table 1

Experiential Literature

Key: N-Norway E-England A-Australia I-Interpretive	***USA***	***Canada***	***Other***	***Grounded Theory***	***Phenomenology***	***Descriptive***	***Informal Caregivers***	***Patients***	***Health Professionals***	***Home***	***Hospice***	***Hospital***	***During Caregiving***	***Post Caregiving***	***General***	***Terminal***
Authors	**Country**			**Design**			**Sample**	**Size and**	**Group**	**Site**			**Interview**		**Cancer**	**Trajectory**
Thorne (1984)		#			#		12	8		#			#		#	
Matson (1988)	#			#			11		9		#		#			#
Hull (1989, 1990, 1992)	#					#	14			#			#	#		#
Davies et al. (1990)		#		#			24			#		#	#			#
Martens & Davies (1990)		#				#	45	45		#			#			#
Norum (1995)			N			#	21			#				#		#
Rose (1998, 1999)			E		#		21			#			#	#		#
Yates & Stetz (1999)			A			I	20			#	#	#		#		#

The experiential literature discussed the informal caregivers' experiences during palliative cancer care in terms of the stress that occurred during caregiving (Matson, 1988; Hull, 1990; Norum, 1995; Martens & Davies 1990; Rose, 1998, 1999) and the ways in which the caregivers managed themselves (Thorne, 1984; Matson, 1988; Hull, 1992; Norum, 1995; Rose, 1998, 1999; Martens & Davies 1990). Researchers also conceptualised the caregiving period as a journey with various stages for the caregivers (Hull, 1989; Davies, Reimer, & Martens, 1990; Yates & Stetz, 1999).

Stress was due to a number of factors such as accepting and adjusting to the caregiving role as well as maintaining other family roles and responsibilities. These factors included dealing and communicating with others (friends, health professionals), deterioration in the condition of loved one, uncertainty due to the uncontrolled and unknown changes, lack of information, fatigue and anxiety (Martens & Davies 1990; Matson, 1988; Hull, 1990; Norum, 1995; Rose, 1998, 1999). Sources and strategies utilized by caregivers during this time included interpersonal relationships (family and friends), support and information from health professionals, effective time management, and focusing on the day to day caregiving tasks (Thorne, 1984; Matson, 1988; Hull, 1992; Norum, 1995; Rose, 1998, 1999; Martens & Davies 1990). Informal caregivers found strength during caregiving primarily from the adoption of an inner positive attitude. This included hoping for the best, reflecting on the past and evaluating the situation, finding windows of time to self-energize, not dwelling on the inevitable death, and looking for and finding meaning in the situation (Thorne, 1984; Matson, 1988;

Hull, 1992; Norum, 1995; Martens & Davies 1990). The finding of meaning in caregiving was not described in depth in the literature reviewed above. However, it was noted that finding meaning had a positive influence on the management of the caregiving experience.

Authors who considered the caregiving experience as a journey described it as a process. Hull (1989) perceived it as a process consisting of four stages: confronting the reality of the loved ones' terminal state; surveying the options of care (home-based, hospice, etc); being immersed in the caregiving role which included the stresses and self management; and refocusing on self in a new situation which included the closure of the caregiving role. Caregiving was described as transition of fading away by Davies et al. (1990). It was expressed as a three stage process: The ending was characterised by recognition of the loved one's unrecoverable state and self-redefinition as well as dealing with caregiving in light of this awareness. The neutral zone was an experience of emptiness characterised by fear and uncertainty – caregivers struggled with issues of living and dying and the changing roles and relationships – the search for meaning occurred during this time. The beginning involved a reorientation of self to life/death and included personal growth.

Yates and Stetz (1999) described the informal caregiving experience as caregivers' development of an awareness of dying. The process was found to develop gradually and was distressing to the caregivers. It consisted of five themes: 1) Uncertainty about the present/future illness circumstances. 2) Agonising, characterised by emotional struggles to developing an awareness of

dying. 3) Hoping, consisting of deliberately reframing perceptions to envision a positive future. 4) Pretending, comprising acknowledgement of the loved one's dying but acting as if they would continue to live. 5) Preparing, when caregivers started to make public and private preparations for the death. The above literature provided a holistic picture of the caregiving experience and also stated that the search for meaning occurred during the caregiving journey yet the meaning in the caregiving experience was not clearly ascertained.

Meaning in Caregiving

Meaning is a deceptively simple term. Among the many definitions given for the term in the dictionary is 'the sense or signification of' (Webster's dictionary, 1989). This does not say much for the complex concept of meaning. According to Richer and Ezer (2000) the concept of meaning is presented in two ways in literature: one relates to the individuals' perception of their place in the universe (existential meaning) and the other is the ways in which individuals evaluate specific events (situational meaning). Existential meaning is the meaning of life; human beings need meaning in life, loss of meaning leads to existential despair/vacuum – the search for meaning (which must be individually discovered) is the primary motivational force in people (Frankl, 1946/1984). Situational meaning is found within a specific event; the meaning in the moment (Frankl, 1946/1984).

According to Fabry (1996) meaning is elucidated in five areas: 1) Self discovery is when we truly see ourselves. 2) When we perceive and make choices. 3) When we discover our own uniqueness. 4) In responsibility when responding

to the meaning of the moment from our conscience and rising to the sense of responsibility to another. 5) Through transcendence. Transcendence combines the other four areas: "In transcending ourselves we get a glimpse of our authentic self, we do make a choice, we feel unique, and most of all, we assert our responsibility" (p. 114). Kellett (1997) stated that it is the "caregivers' ability to be conscious of themselves, their ability to view their lived experience and attribute meaning to such experience, that enables them to ascribe meaning to their existence as caregivers" (p. 59). Research by Baum and Stewart (1990) on sources of meaning across the lifespan revealed a number of meaningful event categories one of them being accidents, illnesses, or death. Critical life periods or events therefore may provide meaning to the people experiencing them as they cause the people to re/appraise themselves within a given situation. Home-based terminal cancer caregiving is one such event.

Minimal information was found within the cancer caregiving literature on meaning in the caregiving experience. A study by Ayres (2000) on the meaning in caregiving though not specific to terminal cancer caregiving described the process caregivers went through to find meaning in their caregiving experience. The author stated that caregivers integrated caregiving in the larger context of their lives by the use of expectations based on life experiences and explanations based on personal philosophies, moral principles or values, and beliefs about the nature of the world, themselves, families, friends, or caregiving; based on these, they selected strategies to manage the caregiving. Expectations were predictors of what

would happen, explanations provided reasons for the events (past, present, future) and strategies were the action plans used to fulfil the expectations (Ayres, 2000).

Research by Enyert and Burman (1999) on informal caregivers of terminally ill patients noted themes of perspective, context and conditions, actions/process, and consequences. Perspective focused on how meaning was found. Caregivers felt that they were doing something that was important for their loved ones and therefore it was meaningful to them in spite of personal difficulties. Context and conditions described the environment and conditions under which meaning was found. This included: 1) The availability of in/formal support networks. 2) The caregiving actions/tasks themselves. 3) The caregivers' caregiving experience and education. 4) The caregivers' articulation of their grief/loss. 5) Their financial situation and concerns. 5) Caregiver fatigue. 6) The caregivers' experience of multiple tragedies and losses. Actions/process described meaning in the caregiving process which was centered on the ability to 'be with' or 'do for' their loved ones. Consequences involved articulation of a distinct life view that evolved from the caregiving experience and a reaching out to others (family and friends) as a result of finding meaning in caregiving. Though this study was close to the present study, it was from a grounded theory and ethnographic perspective and was not specific to the home-based terminal cancer caregiving experience.

Summary

The research studies reviewed here have contributed to our understanding of the informal caregiving experience. They have given us comprehensive picture of the informal caregiving process. The methodology utilised was descriptive, grounded theory, and phenomenology. Few studies were done from a hermeneutic perspective, which focuses on understanding the meanings behind the experience. These studies on the caregiving experience during terminal cancer care have not explored the meanings in caregiving thoroughly. How informal caregivers interpret and manage their experience during terminal cancer caregiving is dependent on the meanings they attribute to their caregiving experience. A deeper understanding of the informal caregiving experience and the meanings attributed to the experience will enable health professionals to assist the informal caregivers on their caregiving journey. This understanding will also enable health professionals to support the informal caregivers in their search for meanings in caregiving and in life.

The purpose of this interpretive/hermeneutic study was to describe and interpret the caregiving experience of informal caregivers providing home-based palliative cancer care to their loved ones. The study also explored the meanings caregivers ascribed to their experience. The research questions were: 1) What was the caregiving experience of informal caregivers of palliative care cancer patients dying at home? 2) What meanings did the caregivers ascribe to their experience?

METHOD

This study was a secondary analysis of data obtained for a primary study done in June 1999 entitled 'The experience of respite during home-based family caregiving for persons with advanced cancer' (Strang, Koop & Peden, 1999). The interpretive/hermeneutic research orientation was used to guide this inquiry. The secondary analysis, research orientation, data management plus analysis, rigour and ethical issues will be discussed in this chapter.

Secondary Analysis

Secondary data analysis involves the use of an existing data set gathered for a primary research study to answer a new research question or the same question using different methods and can be conducted either by the primary or secondary researcher (Herron, 1989; Hinds, Vogel & Clarke-Steffen, 1997; Jacobson, Hamilton & Galloway, 1993; McArt & McDougal, 1985; Szabo & Strang, 1997). Secondary analysis of a quantitative data set is a common, respected approach for maximising the use of existing data sets; however, its use in qualitative research is a more recent phenomenon as qualitative health research has mostly been limited to primary studies involving human observation/interaction (Hinds et al., 1997; Jacobson et al., 1993; McArt & McDougal, 1985; Szabo & Strang, 1997; Thorne, 1994).

Secondary data analysis offers a number of advantages such as convenience and cost effectiveness, both of which are particularly important in the present climate of reduced research funding (Estabrooks & Romyn, 1995; Herron, 1989; McArt & McDougal, 1985; Szabo & Strang, 1997). It is an

important source of research education for graduate students (Abel & Sherman, 1991; Estabrooks & Romyn, 1995; McArt & McDougal, 1985; Szabo & Strang, 1997). Although the research steps of sample selection and data collection are removed, these can be learned in research courses (Abel & Sherman, 1991; Szabo & Strang, 1997). Secondary analysis is useful for generating nursing knowledge as new questions expand existing knowledge (Estabrooks & Romyn, 1995; Herron, 1989; McArt & McDougal, 1985; Szabo & Strang, 1997). Finally, it contributes to a reduction of respondent burden (Estabrooks & Romyn, 1995; Hedrick, 1988; Szabo & Strang, 1997). This is particularly relevant to qualitative research, as it usually requires in-depth interviews on sensitive subjects. Using the same data decreases the stress placed on participants. As a beginning researcher, it was fortunate for me that I could do a secondary analysis as this enabled me to learn the steps of research without having to go through the time consuming and resource intensive process of obtaining research participants. This was one of the insights afforded to me as a research assistant. The research questions were also sensitive; that is, asking informal caregivers about their caregiving experience and meaning soon after the death of their loved ones. It was particularly important to me that I could ask my research questions and learn the research process without causing added distress to participants.

A major drawback of secondary data analysis is the lack of control over the means of data generation and recording. Lack of involvement in data collection limits the secondary researchers' insight into hidden factors that may influence the outcome of the study (Herron, 1989; Jacobson et al., 1993; McArt &

McDougal, 1985; Szabo & Strang, 1997). Examinations of data for fit with the secondary analysis (questions and methods), ongoing communication with the primary researcher, and in-depth engagement with the data were the primary strategies used to overcome these limitations in the present study. During the analysis, I realised the importance of being involved in the generation of the primary data as some areas of the present study could not be explored thoroughly due to insufficient depth in the data.

Primary Research

The data set that was used in the secondary analysis was collected for a study whose purpose was to explore the experience of family caregiving to persons with advanced cancer, the experience of respite in the caregiving context, and the influence of caregiving on the bereavement process (Strang et al., 1999). The primary study was conducted from an interpretivist orientation, the aim of which is to understand the actions of individuals and the meanings they attribute to them (Guba & Lincoln, 1994; Schwandt, 1994). Ethical approval (Appendix A) was obtained from the Faculty of Nursing, the University of Alberta, and the Joint Capital Regional Health Authority Review Committee (Strang et al., 1999).

Theoretical sampling was used, and the sample size was determined by the saturation of themes (Strauss & Corbin, 1998). Participants were recruited through the palliative home care programs of the Edmonton Capital Health Authority. Criteria included whether caregivers spoke English, lived in the greater Edmonton region, and were caregivers to persons who died of cancer (Strang et al., 1999). Informed consent was obtained, and provision for secondary analysis

was included in the consent form (Appendix B). Demographic data were obtained, and semi structured, open-ended, in-depth interviews were conducted using an interview guide (Appendix C). There were 15 participants and 29 interviews with 2 interviews per caregiver. One participant was unavailable for the second interview. Each interview lasted approximately 60-90 minutes in order to obtain an in-depth understanding between the researcher and participant. The interviews were audio tape-recorded and transcribed verbatim. The first interviews were done between 1 – 12 months post death (mean - 5.3) and the second interviews were between 6 – 18 months post death (mean - 9.9).

Thematic data analysis was done using the grounded theory methods of searching for themes and making constant comparisons. These methods are carefully and methodically developed in the literature and can be used in data analysis even if the aim is not theory development (Strang et al., 1999). Narratives were created for the caregivers to help maintain the context and richness of the stories as well as to outline the uniqueness of each caregiver's experience (Strang et al., 1999).

Secondary Research

There are various approaches to the secondary analysis of qualitative data sets. One approach is to re-analyse all or part of the data set, focusing on a concept present but not specifically addressed in the primary analysis (Hinds et al., 1997). In the present study, both the primary and secondary analyses were concerned with the caregiving experience from the perspective of the caregiver. The primary study identified the concept of the caregiving experience but did not

analyse it in-depth, as its focus was the respite experience. The focus of the secondary analysis was the in-depth analysis of the caregiving experience. The issue of the fit between the data and the present research question was resolved by the fact that both studies explored closely related phenomena (McArt & McDougal, 1985; Szabo & Strang, 1997). The extent of the detail in a data set determines whether valid information can be obtained in the secondary analysis; data collection methods that involve open-ended in-depth interviews obtain more detailed information (Hinds et al., 1997). The sample and data collection methods used in the primary study fitted well with the secondary analysis as both studies were conducted from an interpretivist approach, and open-ended in-depth interviews were used to generate the original data set.

Issues of the suitability of the data for secondary analysis, the monitoring process, and the data access issues (McArt & McDougal, 1985; Hinds et al., 1997) were dealt with through discussions with the primary researcher and provision for secondary analysis in the original consent form. The issue of the sensitivity of the secondary researcher to the research context (Hinds et al., 1997) was addressed by constant communication with the primary researcher, who was also the primary thesis supervisor. The ongoing communication helped to sensitise the secondary researcher to the data and the research context.

Research Orientation

The aim of the present research study was to understand, describe, and interpret the caregiving experience as well as the meaning behind it. The focus of the interpretive orientation is to understand peoples' experiences and the meanings given to them. Reality is thus subjective and multiple, and knowledge is generated by exploring the subjective experiences and meanings (Guba & Lincoln, 1994). Therefore, the most appropriate way to approach this study was via the interpretive orientation. Interpretivists consider research as primarily a practical and moral activity and have argued that there is no external, independent referent point (that can be known as it actually is, in of itself) against which research findings can be measured; they do not believe that there is an objective reality upon which knowledge is based (Smith, 1992).

A situation can have numerous interpretations and reinterpretations based on the interests, purposes, and values of the interpreter. However, for interpretivists, relativism does not mean that anything is acceptable; it simply means that all that can be said about knowledge is that it describes the forms of justification for phenomena that are common to a given society at a particular time (Rorty as cited in Smith, 1992). The present study is a description and interpretation of the phenomenon of caregiving from my perspective yet it is not relative as continuous checking with the primary researcher who was familiar with the data revealed that these interpretations could be made from the data.

Various research methods can be used within the interpretive research orientation as the focus is on experiential understanding. During the present

research, the guidelines outlined in the interpretive inquiry research process (Ellis, 1998; Smith, 1992) and hermeneutic inquiry (Allen & Jensen, 1990; Smith, 1991) were used. The chosen approaches allowed for a holistic, open, unrestricted encounter with the data as they were not restricted by a particular framework. These guidelines enabled me to engage deeply with the data and develop an in-depth understanding and interpretation of the caregiving experience.

Interpretive inquiry is a process or mode of professional inquiry that uses principles and concepts from hermeneutics to guide and monitor the research process and purpose. The three central themes of hermeneutics are: 1) The inherently creative nature of interpretation that requires the interpreter to enter and be one with the person/object of interpretation in order to understand the spirit behind the manifestation. 2) The continuous movement back and forth from the specific to the general or from the parts to the whole in order to achieve a good interpretation. 3) The key role of language in human understanding, how it can enhance or limit understanding and interpretation as it is an essential component of human communication (Ellis, 1998; Smith, 1991). During the research process, I spent a number of months immersed in the data; moving from the data to self-inquiry and back to the data; moving on to the relevant literature and back to the data; going on to the main concepts revealed and back to the data again. This continuous movement back and forth enabled me to understand what I was observing in the data.

According to Smith (1992), the data collection and analysis procedures for interpretive inquiry are similar to those used in other qualitative research methods,

the differences being in the analytic approach to the data. First, the interpretivists hold that self-inquiry in the form of a reflective journal is an important way to proceed. Second, the study is not limited by notions of having to do certain things in order to have a good study, and procedural choices are not constrained by a desire for objectivity but involve moral and ethical choices about how to proceed with the inquiry. Last, though interpretation varies between interpreters and settings, it is not arbitrary. The researcher must be able to defend the interpretation (Smith, 1992). The study is evaluated as acceptable based on evidence of concerned engagement with the data and the clarity and comprehensiveness of the interpretations (Ellis, 1998; Smith, 1992). During the data analysis, I kept a self-reflective journal which consisted of self-inquiry and the questioning of the data as the themes unfolded. The primary researcher who was my supervisor and the thesis supervisory committee were the evaluators of the acceptability of my interpretations.

The process of interpretation proceeds in a circular manner described as the hermeneutic circle. The circle moves in a forward and backward arc between the parts and the whole, the explanations and the understandings, and the interpretations and evaluations. One enters the circle with ones' prejudices, preunderstandings, and forestructures for the purposes of interpretation, and in the backward arc evaluates ones' interpretations to see that which was not seen in the initial interpretations (Ellis, 1998). The preunderstandings consist of background practices from the world that make interpretations possible, background practices that carry with them a point of view from which the interpretations are made, and

background practices that create expectations about what might be anticipated in the interpretations (Geanellos, 1998a). This secondary analysis includes a section prior to my engagement with the data where I clarified my preunderstandings and expectations about the informal caregiving experience and meaning.

Hermeneutics is partly based on the work of Ricoeur who focused on textual interpretations (a text is any discourse transcribed into written word) as the defining element in hermeneutics (Allen & Jensen, 1990; Geanellos, 2000). There are two aspects to textual interpretations (Allen & Jensen, 1990; Geanellos, 2000): 1) The explanations, where data are segmented into sentences and/or paragraphs, categorised according to patterns, compared and contrasted, and integrated into the whole – structural analysis may be used here. 2) The understandings, where the concerns are not with what is described but with what is disclosed, it involves the movement from the superficial/naïve interpretations to the in-depth meanings; overreading, that is, sensitivity to the unspoken or indirect statements in the text may be used here (Poirier & Ayres, 1997). The themes in this study emerged from categorising the transcript sentences and paragraphs according to similarities. The meanings in caregiving were interpreted from the subtle nuances and unspoken statements; they came from being sensitive to the tone of the interviews and the positive expressions of the caregiving experience.

According to Gadamer (1975), to understand the texts, we do not have to put ourselves in the place of the others but to simply grasp the meanings, significance, and aims of what is transmitted to us in the texts. The fusion of horizon occurs between the texts and the interpreter (researcher) and is influenced

by the researchers' preunderstandings which result in different interpretations of the same texts. Geanellos (1998a) argued that the interpreter (researcher) therefore becomes a mediator between the text and all it implies but not the interpreter of what the author (research participant) meant. Therefore, researchers using Gadamer's fusion of horizons do not need to check their interpretations with the research participants (Geanellos, 1998a). The data spoke volumes to me: I saw the richness of the caregiving experience in it. I did not feel the need to check my interpretation with the research participants as my interpretations were based on the data itself. However, for the theme of transformation, I found the data limited and in this instance I felt I needed additional information from the participants.

Data Management

Data management refers to the systematic process of data collection, storage and retrieval operations aimed at ensuring high quality accessible data (Huberman & Miles, 1998). The original data were obtained via in-depth interviews that were audio tape-recorded and transcribed verbatim. The data were then processed (the transcripts were checked for accuracy with the tapes, the field notes were recorded, and an appropriate coding scheme was developed) and stored securely in an electronic and hard copy format. The tapes were also stored in a secure place.

As the secondary researcher, I rechecked the data for completeness; that is the condition, accuracy, and comprehensibility (Hinds et al., 1997) of the data set prior to the analysis. The data set were found to be in good condition. No major amendments were needed apart from minor corrections of words from the tapes to

the transcripts. Data generated during the secondary research were systematically processed and stored securely in an electronic and hard copy format. Apart from the transcripts and the demographic data on the caregivers, a profile of each caregiver was generated as part of the secondary data set. The data also included an audit trail of the analysis process consisting of the meetings and discussions of the data with the primary researcher and the self-reflective journals maintained during the analysis process.

Data Analysis

Data analysis proceeded in a circular manner (hermeneutic circle/spiral) starting with a description of personal preunderstandings. It continued with the listening of the tapes, the reading of the field notes, transcripts, and discussions with the primary researcher to obtain a feel for the data. These also included personal debriefing and confirmation of follow up for some caregivers; as in some instances acute distress was noted in the interviews and as a secondary researcher I was concerned as to how this was handled during the primary study. Lastly, interpretations were made by finding similar patterns within and across the cases and by going back and forth from the parts to the whole of the text.

The interpretations were constantly discussed and evaluated with the primary researcher/thesis supervisor. Continuous engagement with the related literature informed my understandings and subsequent reinterpretations were made. A concerned intense engagement with the data, the forward/backward movement in the interpretation process, and the audit trail/personal journal

enabled me to increase my understanding of the caregiving phenomenon and to describe my interpretations in depth as well as show how they were derived.

Preunderstanding

My preunderstandings were brought into consciousness by describing my personal beliefs and thoughts about the informal caregiving experience based on my personal/professional experience and my encounters with the phenomenon in the literature. Prior to engagement with the data, I described my interpretations of the informal caregiving experience and my expectations as to what I may encounter during the data analysis. This was done by on my part by responding to the interview guide based on my experience of my mother's death due to cancer and by writing a reflective account about in/formal caregiving (Geanellos, 1998b). The intent was to be aware of my personal preunderstandings with which I would enter the hermeneutic circle/spiral, as these would have an effect on the interpretations that I would make.

Context

Interpretation is the outcome of the involvement of the interpreter/researcher and the text/interview transcripts to be interpreted. However, the context within which the text was obtained also informs the interpretation process (nuances, tone of voice, body language etc). With secondary data analysis, it is not possible to obtain the experience of the context of the data collection as the data are already processed and available in the form of a text. This limitation of the secondary data analysis was dealt with as well as the accuracy of the data/text checked by listening to the tapes of the interviews,

reading the field notes, and via discussions with the primary researcher to clarify issues. This process enabled me to get a feel for the data and be immersed in it. In some instances, the engagement was fairly intense such that I needed to debrief with the primary researcher especially during the beginning stages of analysis.

Technique

According to Morse (1994), qualitative data analysis involves four cognitive processes: comprehension – identifying the themes; synthesis – merging of the themes to make a composite pattern; theorising – connecting the findings with the larger body of knowledge; re-contextualisation – applying the findings to other settings or the context in which the findings fit. These processes were applied to the data analysis within the interpretive inquiry framework. Specific techniques used within the hermeneutic circle/spiral of interpretation included thematic analysis within and across cases. In this case, parts of the data containing similar concepts within one transcript were collected into categories and then similar concepts from different transcripts put together to find common patterns in the data. Other techniques used were structural analysis and over-reading.

The hermeneutic circle/spiral is an interpretive strategy designed for the identification of meaning from the texts/narratives; as more information is obtained, previously identified information takes on a different meaning as part of the developing whole (Ellis, 1998; Ayres, 2000). This process of interpretation took place during the analysis that proceeded from naïve/superficial to deeper levels continuing in a spiral form and was similar to the constant comparison method used in grounded theory (Ayres, 2000). Constant comparison involves

comparing pieces of information from within and between the texts for similarities and differences between them; these are then classified into conceptual categories/themes and compared to the related literature to search for the presence and explanation of the phenomenon (Strauss & Corbin, 1998).

Structural analysis is used to seek explanation for the phenomenon in terms of the underlying rules and principles that produce the surface interpretation. Meaning in the analysed text is assumed to be dependent on, and constructed by the language (Manning & Cullum-Swan, 1994). Within the hermeneutic circle, structural analysis was regarded as a stage between surface and depth interpretation; it provided the explanation which in turn helped with the understandings (Ricoeur, 1970-1979/1981). A qualitative researcher is an overreader; that is, she is sensitive to the unspoken or indirect statements in the text (Poirier & Ayres, 1997). Overreading involved paying attention to the silences, repetitions, omissions, and inconsistencies in the texts. It helped to disclose deeper meanings in the interpretation process.

Outcome

The results of the secondary data analysis include a comprehensive, coherent and plausible interpretation of the caregiving experience of the informal caregivers and the meaning of caregiving to them. The preunderstandings and reflections provide my understanding of the caregiving phenomenon and the personal growth achieved. Interpretations are based on the interaction between the researcher/interpreter and the research/data/text. This means that the interpretation that I have arrived at may differ from another researcher's interpretation of the

same text; however, it is expected that the readers will be able to follow my interpretation even though they may not share it. The audit trail recorded and explained the actions taken during the analytic process. My personal transformation is reflected in the personal journal and summarised in the reflections section in results.

Illustration

The interpretation process primarily involved the hermeneutic spiral. I will briefly explain the process as it unfolded during the data analysis. This process is also illustrated in Figure 1 largely using the theme of love. The interpretation process is an ongoing activity and a conscious decision in collaboration with the primary researcher was made to stop at the diagrammatic representation of the caregiving experience. After my preunderstandings were brought into awareness, the interviews were heard and read a few times to get a feel for the data and check its accuracy. These initial naïve or superficial readings provided me with an overall picture of the caregivers based on which the caregiver profiles were generated. These naïve readings revealed the dominant issues in each interview. In some interviews, the predominant feeling/emotion that came out was positive (love, bond with the loved one, being together, etc.); while in others it was negative (suffering, frustration, missing the loved one, etc). At this stage, I also saw that the terminal caregiving period was a critical time period for the caregivers. The main domains that emerged in these naïve readings were that of the caregiving context and the positive and negative experiences of caregiving.

I reflected on these preliminary readings, re-entered the hermeneutic spiral, and moved from superficial to deep levels of interpretation. Here the technique of constant comparison and structural analysis were applied. Segments of texts consisting of sentences and paragraphs that related to the three domains identified above were transferred from the transcripts to a new document created for each theme. Units of information were selected from each interview and across the interviews according to similarities and differences between them. A number of units of information emerged here that were different yet overall similar. These were categorised as sub-themes within the main themes. For example, caregivers talked of the connection with their loved ones and wanting to be with them. I saw these as different yet similar expressions of the positive emotion identified above.

In my personal journal, I noted that the caregivers were expressing their love for the person they were looking after. My uncensored thought was, "I cannot call this theme love. It does not sound scientific." Visions of romantic love appeared before me. The audit trail included issues such as: What is this feeling that I am seeing? How do I interpret it? Is it happiness or satisfaction? But it is more that all that, though there are similarities in all these statements. In the discussion with the primary researcher, my predominant thought that this was love came out as well as my discomfort with using love to identify the theme. I decided to identify the positive emotion noted as love for now so that I could continue with my thinking process and the hermeneutic circle/spiral. In this manner, I was aware of my personal biases and thinking as well as of the data.

While I was engaged with the data in this manner I started noting other salient issues that I had not observed in the data before. What I was actually doing here was 'over-reading', and I apprehended that the caregiving experience had a profound effect on the caregivers. I could see this, but could not identify the concrete segments of information that alluded to this issue. As the process continued, I realised that what I had noticed was a subtle sense of change/transformation that was expressed by the caregivers. Therefore, the theme of transformation emerged at this point in my interaction with the data.

My movements within the hermeneutic spiral continued. I now explored my understandings on the three themes of love, suffering, and transformation in literature. For example, with the theme of 'love' this process included exploration of the vast literature on love from fictional, philosophic to psychological literature. I gained a deeper understanding of, and comfort with the subject matter and the terminology. I then re-examined the data with a fresh view and understanding based on what I had learned. The above sub-themes of bond, being together, etc. were now reinterpreted and explained as various manifestations of love. In understanding my data, I indirectly understood myself (Ricoeur, 1974).

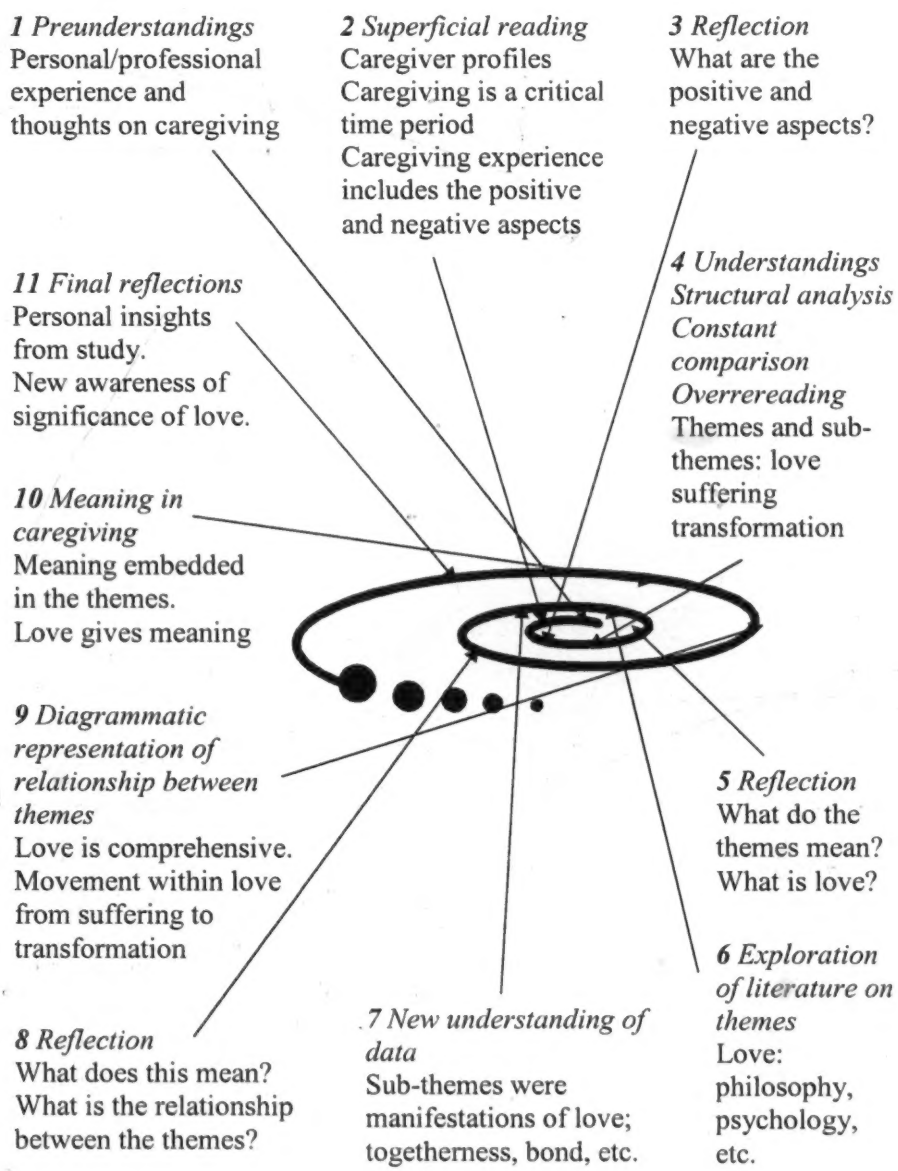
I now had the two aspects of caregiving; the context included the caregivers' description of this critical/special period of their life and the experience consisted of the three themes of love, suffering, and transformation. My knowledge and understanding of the themes also increased due to the appraisal of the relevant literature. I remained immersed in this total picture of caregiving and re-entered the hermeneutic circle to make the sense of it as a

whole. The audit notes consisted of questions such as: What is the meaning of this? How do all these fit? What is being disclosed to me here?

I finally came up with a diagram of the relationship between the three themes. Here I was interpreting at the level beyond explanation to understandings. In the diagrammatic presentation, love was the comprehensive emotion which existed before, during, and after the caregiving time period; it provided purpose and motivation for caregiving. I interpreted the whole process in terms of a journey or movement within love, from suffering to transformation. The meaning in caregiving was embedded in this journey. The process was interpreted with regards to the caregiving experience in the present study; however, I could see it occurring in other critical situations as well (for example major life changes). My final reflections made me critically aware of the significance of love to caregiving. My journey of data analysis illustrated primarily with the theme of love shows the application of the cognitive processes of comprehension, synthesis, theorising, and recontextualising outlined by Morse (1994).

Figure 1

Hermeneutic Spiral or Circle


1 Preunderstandings
Personal/professional experience and thoughts on caregiving
2 Superficial reading
Caregiver profiles
Caregiving is a critical time period
Caregiving experience includes the positive and negative aspects
3 Reflection
What are the positive and negative aspects?
11 Final reflections
Personal insights from study.
New awareness of significance of love.
4 Understandings
Structural analysis
Constant comparison
Overrereading
Themes and sub-themes: love suffering transformation
10 Meaning in caregiving
Meaning embedded in the themes.
Love gives meaning
9 Diagrammatic representation of relationship between themes
Love is comprehensive.
Movement within love from suffering to transformation
5 Reflection
What do the themes mean?
What is love?
6 Exploration of literature on themes
Love: philosophy, psychology, etc.
7 New understanding of data
Sub-themes were manifestations of love; togetherness, bond, etc.
8 Reflection
What does this mean?
What is the relationship between the themes?

Rigour

Guba and Lincoln (1981) have argued that trustworthiness of qualitative research needs to be established using concepts that are appropriate to the philosophical assumptions of the research paradigm. In this study, which was guided by the interpretive research orientation, trustworthiness was achieved using the criteria of credibility and auditability.

Credibility

Credibility refers to the truth-value of the findings or interpretations. In qualitative research credibility measures the vividness and faithfulness of the descriptions; that is, how well a reader can relate to the described experiences (Beck, 1993). This was achieved in the present study by strict adherence to the text during the analytic procedures and by ongoing discussions and evaluations of the findings and interpretations with the primary researcher and the supervisory committee. They were the readers who validated the plausibility of the interpretations. Credibility of qualitative research is enhanced when the researcher describes and interprets her own behaviour and experiences in relation to the behaviour and experiences of the participants (Sandelowski, 1986). In the present study, my preunderstandings were made explicit prior to engagement with the data, and a personal journal was kept during the analytic process to clarify how the research process influenced me and increased my self-awareness. The final reflections in the results section describe my personal learning and insights.

Auditability

Auditability refers to the consistency aspect of rigour (Guba & Lincoln, 1981). It consists of keeping an audit trail during the research process and refers to the ability of another researcher to follow the trail to see how the interpretations were achieved. A qualitative research audit trail comprises various research-generated materials that are consistently and conscientiously recorded in an organised manner during the research process (Rodgers & Cowles, 1993). The research audit trail consists of: the observational/field notes related to the contextual background of the data; the notes on the methodological decisions and their rationale; the analytical/theoretical notes on the analytical insights achieved during the sorting, categorising, and comparing of the data; the personal reflective documentation consisting of uncensored feelings/statements about the research process (Richardson, 1998; Rodgers & Cowles, 1993).

The present research was a secondary data analysis; therefore, there were no field notes but field notes from the primary research were referred to for contextual information. An audit trail (electronic/handwritten) was maintained of the methodological, analytical, and theoretical decisions made and their rationale, and the insights attained, this also included meetings and discussions with the primary researcher. A handwritten personal journal was also maintained.

Ethics

The consent obtained for the primary study included provision for the secondary data analysis. This provision was subject to the secondary study receiving approval from the ethics review committee. Ethical approval was

received from the Health Ethics Review Board (Panel B), the University of Alberta for the secondary analysis (Appendix D). A secondary analyst is bound by the same privacy and confidentiality restrictions as the primary researchers and is legally responsible for any breach of ethics in the conduct of the study (Burstein, 1978); these principles remained applicable to the present study.

A letter of agreement (Appendix E) that outlined the rights, responsibilities, and obligations of the secondary and primary researchers was signed prior to the commencement of the secondary analysis. The letter included a description of the data to be accessed (interview tapes, field notes and transcripts) and "how appropriate reference citations and acknowledgements of the original researcher will be provided in subsequent publications and scholarly presentations" (Estabrooks & Romyn, 1995, p.82).

FINDING AND DISCUSSION

The primary study examined the experience of respite (Strang, Koop, & Peden, 2002), the bereavement outcomes (Koop & Strang, 2003), and caregiver coping (Strang & Koop, 2003) for family caregivers of advanced cancer patients. The focus of this study was the informal caregiving experience and meanings during home-based palliative cancer care.

The results of this secondary analysis consist of my preunderstandings with regards to caregiving prior to data analysis and the demographic data on the participants together with their profiles using pseudonyms. The context of the caregiving experience is described and discussed in terms of the perception of time and space during caregiving. The caregiving experience, consisting of the themes of love, suffering, and transformation, is described and discussed. The meaning embedded in the caregiving experience is examined as it evolved from the themes. The results and interpretations are then related to the literature on informal caregiving. In keeping with the hermeneutic circle/spiral, I conclude with reflections on my learning during this research process.

Preunderstanding

The data analysis includes a summary of my perceptions and understandings with regards to caregiving. These were obtained by answering the caregiver interview guide and by recording my reflections on the caregiving experience based on my professional experience and the literature review. On a personal level, I have not been an informal caregiver; however, I have experienced the terminal cancer and death of my mother. My professional

exposure to terminal cancer caregiving came from my background in oncology and critical care. The answers to the interview guide were based primarily on my experience of my mother's illness and death while my reflections included my thoughts on formal and informal caregiving. I conclude with a description of what I expect to find during the data analysis based on my experience, reflections, and awareness obtained from the literature on cancer caregiving. As per the hermeneutic spiral, I engaged in these reflections in order to clarify and bring into conscious awareness my perceptions about informal caregiving prior to data analysis.

Reflections from a Personal Perspective

I was not a caregiver for my mother yet I felt I had travelled with her during the course of her illness, especially, the last few weeks. Both of us were intuitively aware that she was dying but did not discuss it as we never felt the need for it; I felt we had both accepted it soon after she was diagnosed. I spent a year with her prior to her diagnosis and was thankful for that; I felt it helped us develop a closer understanding and acceptance of each other. I was not with her during the terminal period yet she was my focal point during those last few weeks and they seemed long to me. Because of my professional exposure to dying patients, I could visualise what was happening to her. I felt she was suffering and was waiting for her to die so that she could be 'free'.

Reflecting on that time period, I felt that it was an intense time for me; externally life continued as usual; internally, I lived with my mother and contemplated the situation. For me it was a year of changes; I felt I had grown a

lot during that time. I lived in a state of heightened awareness and my perspectives and thoughts on life and death became clear. I felt I could sense things that others did not and developed a closer and more intense relationship with the Divine.

Reflections from a Professional Perspective

Within the hospital setting, I was impressed by some informal caregivers and their loved ones who seemed peaceful during their last few hours/days; they and their loved ones seemed to have come to terms with their condition and death. These caregivers seemed to be different than others and I would feel like an outsider observing something special. When I think of these caregivers and myself as a formal caregiver: I feel there is a major difference between the formal and informal caregiving experience. The actual caregiving tasks may be similar but the attitude towards caregiving is different. Formal caregiving is part of the health professionals' work; they have the knowledge and skills needed to provide the care, and do so to the whole family. However, the emotional ties that are part of the informal caregiving experience do not exist to the same extent with formal caregivers though the health professionals have empathy and understanding of the situation.

Informal caregivers are deeply involved with their loved ones and the caregiving experience is part of their life experience. Informal caregivers accompany their loved ones on their journey through the illness and suffering and seem to have difficulty switching off or taking time out. Not having experience or knowledge of caregiving may make it difficult for informal caregivers to be sure

of their skills and to acknowledge to themselves that they are doing all that they could to make their loved ones comfortable. This may lead to stress and uncertainty.

It is my perception that it is much more difficult to be an informal caregiver than a formal caregiver. Informal caregivers may achieve deep personal growth and changes from their caregiving experience and the suffering they undergo together with their loved ones. Being an informal caregiver enables one to think about life and death from a closer personal perspective. Informal caregivers therefore may achieve transformation and experience greater clarity in their values and beliefs with regards to life/death and the Divine.

Summary of Reflections and Expectations

The literature review focused on the experiential literature during terminal cancer caregiving as these studies were relevant to the present study. However, I examined other literature on home-based informal caregiving during advanced cancer disease; this included literature on the needs of informal caregivers, impact of cancer on informal caregivers, and the quality of life of informal caregivers of cancer patients. Therefore, my perceptions and expectations are based on this inclusive picture of informal caregiving obtained from my personal/professional experience and my readings of the cancer caregiving literature. My general understanding is that informal caregivers undergo considerable distress, almost the same as the patients themselves. This distress includes physical (fatigue, illnesses), mental/emotional (stress, fear, uncertainty, loneliness, powerlessness), and spiritual (existential/spiritual conflicts) components. I feel that informal

caregivers may go through a period of transformation in their life, which may cause personal growth and maturation signified by the changes in their attitudes towards life and death and clarification of their values and beliefs. This could include increased or decreased faith in the Divine will/powers. These changes may be related to how the informal caregivers reflected on and interpreted their caregiving experience and the meanings in it.

Demographic Data

The study participants consisted of 11 women and 4 men. There were 6 wives and 3 husbands, 1 son, 3 daughters, 1 daughter-in-law, and 1 sister. Their age ranged from 37 - 81 years with a mean age of 60.3 years. Their education ranged from university (3), college (4), and high school (7) to elementary (1). About half of the participants were healthy or only had minor health problems during the caregiving time period; others had more major concerns related to the heart, blood pressure and other problems. Study participants provided care to family members with various types of terminal cancers and the intense terminal caregiving time ranged from 1 – 11 months with a mean of 4.3 months.though in some cases the participants considered themselves as caregivers for longer periods of time. Table 2 provides the demographic details on the participants.

Table 2

Caregiver Demographics

Name	*Age*	*Gender*	*Education*	*Pt Relation*	*Health Status*	*Pt Cancer*	*Caregiving Period*	*Int 1*	*Int 2*
Anne	81	F	College	Wife	Knee Injury	Prostate	3 m (5 yr) (1.5 m-H)	4 m	8 m
Betty	37	F	College	Daughter	Healthy	Ovarian	3 m (4 yr)	11 m	13 m
Colin	49	M	Grade 12	Son	Healthy	Breast	3 m (4 yr)	4 m	7 m
Dave	78	M	Grade 11	Husband	Pneumonia	Lung	4 m (3 yr)	11 m	16 m
Erin	48	F	College	D-in-law	Healthy	Unsure	5 m	4 m	9 m
Fran	56	F	Grade 12	Wife	Heart	Liver	3 m	5 m	9 m
Gina	48	F	University	Daughter	Diabetes	Lung	6 m (3 yr)	3 m	10 m
Harry	77	M	Grade 7	Husband	High BP	Colon	6 m	6 m	10 m
Irene	63	F	Grade 12	Wife	Lung/Breast Ca	Liver	4 m	12 m	18 m
John	76	M	College	Husband	Healthy	Lung	11 m (1 m-H)	3 m	8 m
Kim	57	F	Grade 11	Wife	Neck Injury	Oesophagus	6 m	2 m	7 m
Lily	49	F	University	Sister	Healthy	Lung	7 m	1 m	9 m
Mary	41	F	University	Daughter	Back Injury	Cervix	1.5 m	6 m	Nil
Nina	75	F	Grade 12	Wife	Heart/High BP	Lung	1 m	5 m	8 m
Olive	69	F	Grade 12	Wife	High BP/TIA	Prostate	1.5 m (1.5 yr)	3 m	6 m

Caregiver Profile

A profile for each study participant was generated based on the interviews and field notes using pseudonyms. The profile provides my perception of each research participant as obtained from the data; that is it is a general overview of the study participants as interpreted from the data.

Anne:

Anne was 81 years old with college education who considered herself healthy other than having a limp from an old knee injury. Her husband had prostate cancer for 5 years and she was the caregiver for the last 3 months. Her husband was admitted on a palliative care unit in a continuing care facility for the last 6 weeks. She lived alone in a bungalow, was independent, and had a supportive network comprising of family, friends, neighbours and membership in a group/society. The interviews were done 4 and 8 months post death. Anne was friendly, comfortable, and talkative during the interviews. Anne described her caregiving experience as positive and was happy to have been able to do it.

Anne had a lot of information to share; she talked a fair amount about her beliefs, attitudes, and life experiences which led to her growth and helped her during the caregiving period. She had a practical matter of fact attitude towards life, which included dealing with issues the best that one could. She believed in looking after herself "I made sure I got enough sleep; I made sure I got the meals in normally", and felt that she had a flexible attitude to life: "I am pretty easygoing on the whole and I am not rigid in anything". She felt she managed the practical caregiving tasks due to her attitude of seeing her husband as a sick

person who needed to be looked after: "I was able to wash him and do all the things you do for a sick person".

Anne had a strong faith in God and felt that this was her main source of strength in dealing with issues in her life: "That [God] is where you get your biggest strength . . . you can draw on that, it makes you strong and it makes you very positive". A memorial service held by her group/society was considered extremely helpful by Anne in coming to terms with the death of her husband and was vividly described during the interview: "As I said, the memorial service just shocked me out of everything and I deal with it realistically and I told you I found the presence in the house. D is still here but he's not alive but there is a presence . . . he's very much around and yet he isn't real".

Betty:

Betty was 37 years old with college education and no health problems. Her mother had ovarian cancer for 4 years and required care during the last 3 months. However, Betty considered herself the caregiver throughout her mother's illness due to their close relationship. She lived with her partner in a separate condominium in the same building as her mother. Betty, her partner, family, and friends worked together as a team to provide care for her mother. The interviews were done 11 and 13 months post death. During the interviews Betty was friendly, comfortable, and openly shared her reflections on her experience although at times she was tearful and overcome by grief. Betty's partner participated in the second interview towards the end to provide more insight and a different perspective on Betty's experience. Betty described her caregiving experience as

positive and powerful due to the intense connections with others in the caregiving team. She considered it a privilege to have been her mother's caregiver.

Betty described her total involvement with caregiving: "There was nothing else in life except taking care of my mother, there was no other life and it was great, I mean that was it". The intense connection and support between the members in the caregiving team was frequently brought up: "There was probably ten of us that was like this team . . . the emotional support it was just like this really intense connection with everybody, we all had a goal, we all had a project, we all knew what we needed to do and it worked, it was great". Betty also elaborated on her close connection to her mother: "I had a very unique connection with my mother, I realised that it was a very rare kind of relationship . . . soul mates you know". Though the interviews were conducted almost a year post death Betty was still going through intense grief and spoke about her grieving process: "Now I have fleeting thoughts of her in her healthier times . . . just the last few months and her actually dying was so vivid and so traumatic, so I am feeling a little bit of a switch there. So it is just really painful still . . . I am not feeling her yet, I don't feel her presence yet". In the interviews, I sensed that Betty had undergone a number of changes due to personal reflection on her experience.

Colin:

Colin was a healthy 49-year-old businessman with a high school diploma who had a close relationship with his wife. His mother had breast cancer for 4 years but required care for the last 3 months. For this, she had moved in with Colin and his wife in a condominium building and died at their place. Although

Colin was the primary caregiver, he felt that both he and his wife were partners in the caregiving process and her support was crucial to him. The interviews were done 4 and 7 months post death. Colin's wife was present during the first interview and contributed to it but was not there for the second one. Colin was gracious, organised, and referred to his journals containing a detailed account of his mother's health status during the interviews. Colin described his caregiving experience as critical and a trust placed on him. He felt that it was the best thing that could have happened to them and was grateful that they could do it.

Colin expressed his frustrations with the inadequate pain management for his mother: "The pain is something that just drives me crazy . . . I finally called him [the doctor] myself once and told him . . . this has got to stop". He described their total involvement with caregiving: "We were into it and that's what consumed our thoughts and times and our meals and everything". He cherished the fact that his mother trusted him enough to place herself under his care: "I mean it is quite a thing to have someone, I mean your mother say yes she wants to be here in your home. . . . Obviously this is where she wanted to be and trusted that I would look after things, whether it [be] financial affairs or her well being or whatever". Colin elaborated on his bereavement process and the images he had of his mother's last days: "I look at her picture [taken when she was well] and it lasts about five seconds and it goes to what she looked like when she was gone. And that hurts me because obviously she was skin and bone and grey colour".

Dave:

Dave was 78 years old with high school education who stated he had no health problems other than that he was ill with pneumonia shortly after his wife's death. He was the caregiver for his wife for 3 years as she suffered from polymyalgia rheumatica. She had lung cancer for 2 years and required intense care for the last 4 months. They lived in a townhouse built for seniors; he continued to live there but had difficulty staying at home due to the vivid memories of his wife's death in the same house. Therefore, he was out often and visited his daughter each evening for supper. The interviews were done 11 and 16 months post death. Dave was courteous and friendly but seemed overwhelmed with his grief which he struggled to keep under control as he felt it was not appropriate to show emotions. He was tearful but more comfortable during the second interview; by this time he was able to stay at home longer though he still went out often. Dave described his caregiving experience as intense and involved. He expressed his satisfaction that he had done his best for his wife.

Dave's difficulties with staying home came out distinctly during the interviews as he described the effect of home death on his present state of being: "The house was; that was the death chamber and of course every time I come into this I would think of that and I just hated to come home and I hated to go into the bedroom particularly . . . the house drove me out and even yet I'm out by noon or 1 o'clock. I just have to get out of the house; I just can't stand to sit here". Dave's total involvement with the care of his wife was evident: "that [caregiving/illness] is what dominated the whole thing". Though it was 11 and 16 months since the

death of his wife, Dave was still in intense grief and missed his wife acutely: "I never go through that two hours without her coming in, in my thoughts, and sometimes very strongly too, even though everybody is around me". Dave also commented on feeling his wife's presence with him: "As I say all I feel is a presence there and I can't get a picture of her but I can get the presence".

This was a difficult interview to analyse due to the prominent feelings of distress and grief expressed by the participant. There was a sense that Dave felt lonely, isolated, and did not want to reflect deeply on his caregiving experience because it was painful for him. He seemed to have stopped doing certain activities because they brought back painful memories of his wife. He also conveyed a sense of loss of purpose and just seemed to be 'hanging around' finishing his days, it seemed that his wife was his aspiration for being and with her gone he felt lost: "You know they talk about being a stranger in a big city and that's the way I felt completely that I was absolutely lost no matter what I did. I still do at times. I most certainly don't forget about her".

Erin:

Erin was an independent 48-year old with a college education who had no health problems. Erin was a practical nurse and provided care for her mother-in-law for the last 5 months; she was not working at that time. Initially her mother-in-law was in her own home but for the last 2 weeks, she moved in with Erin and her husband. Erin had a close and loving relationship with her mother-in-law. The interviews were done 4 and 9 months post death. During the interviews, Erin was friendly, talkative, and shared her thoughts and feelings openly. Erin described

her caregiving experience as complete, fulfilling and beautiful. She considered it a gift that she could care for her mother-in-law.

Erin talked about her connection with and her high regard for her mother-in-law: "I could feel what she felt . . . I mean we really understood each other's needs . . . needs to be alone, needs to be quiet". She talked about her caregiving experience as being focused, consisting of anticipating the needs of her mother-in-law: "Probably what kept me the busiest was anticipating what she needed because I knew she wouldn't ask". Erin found the death experience beautiful and described it in detail: "I just knew that it was going to be right away, we would say we were so attached to the hip that we were starting to think alike. So I just went in and I guess held her hand and talked to her and then she died. . . .I saw her die I knew, I felt her spirit leave the room, she was gone". Erin was open about her feelings of grief and bereavement: "The grief was so intense and just missing her was so intense. . . . The acuteness is finally lost, only about a month ago . . . it was very acute for me it was more acute than any other grieving".

Fran:

Fran was 56 years old with high school education who had heart problems for which she was on medication. She provided care at home for 3 months for her husband who died due to liver cancer. They lived on the farm; during the interview Fran's daughter was living with her. Fran was a strong, independent lady who was very involved with raising horses. She found this hobby very helpful during the caregiving and post death period. She had a strong and deep relationship with her husband and was close to her children. The interviews were

done 5 and 9 months post death. Fran had a good sense of humour and was friendly during the interviews; she was also tearful at times. Fran described her caregiving experience as emotional and sad but very rewarding and fulfilling. She was grateful she had the strength to do it and felt it was a wonderful thing to do.

Fran appreciated the help from home care as she felt she did not know what to do: "I didn't have any idea what to do, you know, and they [homecare] were wonderful about teaching me". She did not like the brief hospital encounter they had during that time: "The hospital was absolutely the coldest most horrible experience I have ever, ever had to face". She felt the caregiving time was brief and intense: "I think I ran on adrenaline until it was over". She went on to describe her involvement with her horses and how she felt when she was with them: "I would say that the biggest thing in my life for a long time has been my horses and I give myself that everyday".

Fran gave a detailed description of her experiences when she drove with her husband to the Rockies for a last holiday: "It worked out okay except in some ways I think it was more of disappointment for him. Because he was really wanting to do it and nothing turned out, he never left the little bed in the cabin and I think that was really, really frustrating and sad for both of us". She found the post death period difficult and lonely, as it was a big loss for her; she also felt the presence of her husband and still talked to him: "I miss him all the time but when things go wrong I really need him to be here. So we have long talks".

Gina:

Gina, a registered nurse was 48 years old with graduate university education who had diabetes. Her father was diagnosed with and died due to lung cancer in 6 months. Gina had a close relationship with her father and considered herself his caregiver for 3 years. However, her father required intense care for the last 3-6 months. She lived with her husband, son and 2 daughters in a house. Her father lived with them in the basement suite for the last 3 years; he moved upstairs for the last 2-3 weeks. The interviews were done 3 and 10 months post death. During the interviews Gina was friendly and honest in her responses; she was tearful at times and talked about her experiences with the health care system. She was also concerned as to whether she was providing the required information. Gina described her caregiving experience as a responsibility and a stressful period, especially with regards to dealing with the health care system and her siblings but she also appreciated the time she had with her father and said that their bond became even stronger.

Gina described a number of encounters with the health care system where she felt the system had failed her: "I go to the nurse and I ask like what happened, please tell me . . . she goes I'm sorry I'm not allowed to tell you anything I can't tell you anything, no one would tell me anything. That's really, really frustrating". Gina organised her life so that she had time to spend with her father after his surgery, as she wanted to be there: "I had sort of organised myself for that, knowing that he was going to be ill and I had taken a couple of weeks off work, knowing that I wanted to stay home and take care of him". Gina described her

post death experience and compared it to her mother's death, which was a sudden event. She felt it was easier to deal with the grief after her father's death because she had more time with her father: "When my Mom died, she died quite suddenly . . . my grieving was really intense and just kind of horrific . . . for my dad I was able to know that he was cared for and someone was always there for him". Gina stated that she felt the presence of her parents around her: "Sometimes I feel him there, my mom used to come and help me write exams".

Harry:

Harry was 77 years old with elementary education who was on medication for hypertension. He had a close relationship with his wife who had colon cancer for over 4 years and required intense care for the last 6 months. He lived alone in a duplex but was in contact with his daughter and 2 sons; one lived out of town and one was mentally challenged. He seemed lonely, had minimal social support and did not go out much. The interviews were done 6 and 10 months post death. During the interviews Harry was polite and friendly but seemed overwhelmed with grief at the loss of his wife; he was emotional and tearful. Harry described his caregiving experience as satisfying especially to see his wife comfortable and content and wished he could have done more for her. He was glad to have been her caregiver and said: "It's an all thank you job".

Harry described what happened during the caregiving but did not say much about his feelings and thoughts about it. I got the sense that it was difficult for him to reflect deeply on the situation and his feelings about it as it was too painful for him and he did not want to become emotional. He was totally involved

in the care of his wife and his life revolved around caregiving to the extent that his own health was a secondary issue: "It [blood pressure] was right over the top; a lot of it was I didn't go [for check up]". Harry was still grieving and missed his wife a lot but felt he was doing okay: "She's there constantly and she always will be but I think each day it gets a little easier, I know I never will forget her".

Irene:

Irene was 63 years old with high school education who was diagnosed with breast and lung cancer in the past but considered herself to be in good health now. She had a close relationship with her husband who had liver cancer for about 8 months and required care for the last 4 months. Irene lived alone with her dog in a town outside Edmonton. She seemed to be a strong, independent lady who knew how to maintain her wellbeing. She was close to her children though they did not live nearby. The interviews were done 12 and 18 months post death. During the interviews Irene was friendly and open but had difficulty recalling the caregiving period of time as it seemed to be an event of the past for her. She seemed to have gotten over that phase of her life and did not want to revisit it. Irene saw the caregiving experience more as a part of life and was glad she could do it. She also appreciated the fact that they could be together till the end.

Irene talked about her husband's awareness of when he was going to die and that he planned for it: "Somehow he, and the kids even said that he knew [that he was going to die], because he wouldn't want me to be alone here and maybe he thought I couldn't live in the house if he died here. So he bravely crawled on his stretcher and we went to the hospital". She described her caregiving experience as

focused and unreal: "When I think about it now I think I lived in limbo . . . I don't know, seems almost unreal". Irene discussed how she managed difficult or stressful periods in her life and what she did during her husband's illness and the post death period: "I kept busy crocheting; puttering around the house . . . that's how I cope with things that bother me; is get busy and do something". By the second interview, Irene had worked through her grief during which time she had coped by keeping herself busy redecorating the house: "I think I have come a long way . . . I did things that I don't even remember doing the first 6-8 months . . . but it's not like that now and I don't feel the need to be forever doing something".

John:

John was 76 years old with college education who considered himself to be in good health. He admired, and was close to his wife who had lung cancer and required care for 11 months; both John and his wife stayed in a hospice during her last month. John was active, did voluntary service in the community, and lived alone but was connected to his children. The interviews were done 3 and 8 months post death. During the interviews John was courteous and honest but uncomfortable with his tearfulness; he had an accent, spoke softly, and the interviews were difficult to comprehend. For him the caregiving experience seemed to have been painful due to the suffering of his wife, yet he was glad he could do it and clarified that it was not a burden.

John talked about his wife's accomplishments in painting, arts and crafts: "Her main hobby was doing painting . . . and then she decided to make that hobby worthwhile and try to sell it . . . all the profits were going to those different things

like World Vision". He mentioned his belief in God: "You receive strength from above as you may call it". He also spoke about his grief: "Afterwards you feel very low because she is gone . . . you feel very alone, very much alone and lost". He felt that due to his involvement in the caregiving his grieving was affected: "I have seen too much in the meantime being more directly involved".

I felt that although John wanted to do the interviews it was too early for him and he was still in the acute stage of grief. I felt that he was not able to articulate his own thoughts and feelings with regards to the caregiving period due to the emotions involved in re-visiting the situation (it was too painful for him to go there). His responses focused mostly on what he and others did for his wife and not so much on his own self. He was not able to talk about his experience beyond a certain level as he did not want to get emotional: "Especially talking about her now it brings things all up again . . . this is all from the past anyway so I don't think we have to talk more about that part anyway".

Kim:

Kim was 57 years old with high school education who considered herself healthy other than having a neck injury. She was the caregiver for 6 months to her husband who had cancer of the oesophagus; he required intense care for the last 2 months. Kim loved and admired her husband and was close to her children who were supportive to her. She lived alone presently but her daughter was with them during the caregiving and early post death period. The interviews were done 2 and 7 months post death. During the interviews, Kim was open and at times tearful. She was appreciative of the support received during the caregiving period,

especially from her children. Her daughter, who was also a caregiver, was present and participated on and off in the first interview but was not there in the second one. Kim described her caregiving experience as satisfying in that they could look after her husband at home and he did not have to go to the hospital. She said she was happy she could do it.

Kim and her daughter talked about her husband's attitude which helped them look after him: "He knew everybody was there for him and he was excellent. That's what made it [caregiving] the best". Kim described the difficulties they had to get her husband on the right medications and doses, as he was sensitive to medications: "Like I say, he's very touchy with medications and he went toxic". She talked about the activities they enjoyed doing together while he was ill: "On New Year's Eve, we went to spend it with our friends . . . it was about 12:30 when I took him home." She also expressed their open communications with each other: "We talked a lot . . . he'd talk about all kinds of things, like where do we get buried". Kim described briefly her present state of being: "He often worried about what I was going to do . . . I had said to him don't worry about me no more I will handle it. . . . I think I'm doing well, as well as could be expected".

Lily:

Lily was 49 years old with graduate university education who considered herself healthy. Her sister had lung cancer and she was the caregiver for 7 months at their home where she now lived. She was on leave of absence from her employer for study purposes. Lily was close to her sister and had support from the family and friends during the caregiving period. The interviews were done 1 and 9

months post death. During the interviews Lily was thoughtful, reflective, and tearful. There were long pauses in the interviews where she tried to compose herself before answering the questions. Lily described her caregiving experience as very special but frustrating as well due to lack of personal knowledge with regards to caregiving and death. She was glad she could create and provide for her sister an environment that was flexible and best suited to her. She said she was happy and fortunate that she could be a caregiver to her sister.

Lily described the details of the caregiving period, her total involvement with it, and how her sister got progressively worse: "After she came home from the hospital that was in February that was when the care turned into very intensive full time you know two people care. We needed to massage her a lot, turn her and the whole works". She appreciated the support of others: "People wanted to participate . . . it was good for S too, that many people could participate . . . I had to be there to hold it together but many people were happy to be here". Lily described the difficulties of trying to get and arrange for care: "I think fighting for everything . . . there were just so many different things that were difficult". She also talked about her lack of knowledge about caregiving: "Just to get some direction . . . that what I was doing was the right thing". Lily emphasised the importance of having professionals who saw her sister as a person and not just a patient: "I think the whole, the most critical or the most basic thing you know is that they [formal caregivers] saw her as a person and treated her [as one]".

Mary:

Mary was 41 years old with university education who had back injury 3 years ago which affected her lifestyle and limited her activities. Her mother had cancer of the reproductive organs for a number of years and moved in with Mary for the last 6 weeks. Mary lived with her husband and four children in a house and did not work outside. The first interview was done 6 months post death; Mary was not accessible to arrange for the second interview and it was not done. During the interview, Mary was friendly, talkative and tearful. Mary described her caregiving experience as satisfying in that her mother could be home and she could have quality time with her. She also expressed satisfaction that her children had time with their grandmother. It was difficult as well because Mary had to co-ordinate the care, deal with the formal caregivers, the extended family, and divide herself between her mother and her children.

Mary talked about her difficulties with the physical aspects of caregiving due to the limitations from her back problems: "It was very, very frustrating. . . . I had to have somebody else to help her, I wasn't able to do the bath, the lifting . . . I felt very, very hurt because I didn't have the strength". She discussed her frustrations due to her lack of awareness of her mother's condition: "She was told that five years ago she was in palliative care, that there was no hope for it. None of us knew and it got me mad because I was very furious with the doctors that mom was getting so ill and if she was good why was she getting so ill".

Mary talked about her difficulties with the formal caregiving arrangements: "I found it very confusing because I never knew . . . who was

coming in and some were better with mom and some weren't [formal caregivers]". She also expressed her difficulties with the personal caregiving arrangements: "When mom came, we didn't have everything organised so she took over my daughter's room. My daughter had to sleep in a sleeping bag and mom was mad because she took A out of her room". I felt that the lack of open communication between Mary and her mother because each was trying to protect the other, caused frustration during the caregiving period. I also sensed that Mary felt fully responsible for her mother even though she had her husband and children there for help and support. This caused a lot of stress as she tried to meet the needs of all and organise the care for her mother.

Nina:

Nina was 75 years old with high school education who had heart and blood pressure problems. Her husband had lung cancer for a year and needed care for 5 months especially the last month. Nina was independent, self-sufficient and lived alone in a condominium high rise. She was connected well with other residents in the complex and her friends and daughters. The interviews were done 5 and 8 months post death. During the interviews, Nina was friendly and open. Nina described her caregiving experience as positive and a natural thing to do. She was satisfied that she did everything possible for her husband and was thankful she could keep him home.

Nina appreciated the support from her daughters: "They were both wonderful . . . one of them was here every night with me which was wonderful". Nina described her positive interactions with the health care personnel: "I could

pick up the phone and homecare was right there, they were wonderful". She also talked about the negative aspects: "I thought that is no way to treat anybody if you are supposed to be working with seniors". Nina felt that she blocked out the fact that her husband was dying and went through that time by keeping busy and involved with caregiving: "A lot of that is a real blur so I'm not even sure whether I just concentrated on making meals . . . the medications . . . the washing and the ironing, and whatever". Nina expressed her concern that she may not be facing things, as she should with regards to her grieving process: "I haven't had the feeling of great loss or all the other things that go with death and dying. At first I was mad at him, I was furious with him, everything was negative, but I got over that". By the second interview, there was a sense that Nina had discovered her self, independent of her husband and appreciated her own being.

Olive:

Olive was 75 years old with high school education who had blood pressure problems and had experienced 2 small strokes. Her husband had prostate cancer for 4-5 years and required care for 18 months; the last 6 weeks of which were more intense. During the initial period of illness, Olive and her husband moved into a townhouse condominium in the same neighbourhood as their daughter who was married with four children, in order to be close to the family and medical support. Olive lived there alone now but was close to her daughter who was also a caregiver during the last few weeks of caregiving. The interviews were done 3 and 6 months post death. Both Olive and her daughter, who was a nurse, participated in the first interview; in the second interview, Olive was alone. Both

were friendly and open in their reflections. Olive was more tearful and had a problem with her vocal cords therefore her voice was husky during the interviews. Both described their caregiving experience as difficult but positive and that it included sadness as well as happiness. They were glad and considered it a gift that they could do it; they also found it totally involving.

Olive and her daughter appreciated the support from the family, church, and health professionals: "It was the family help that was the most helpful . . . the church was a wonderful support . . . the healthcare nurses were great". Olive talked about her difficulties with the health professionals: "They [formal caregivers] didn't know how to fit in; they weren't sensitive to the situation". She also spoke about the expenses of home caregiving: "It cost me a lot more than it would have in the hospital". Olive's daughter talked about their close relationship with their father: "We would hate to miss out on that deepening of the relationship with our father". Both Olive and her daughter described the last 2 weeks of caregiving as physically demanding: "It was very; very intense . . . it was 24 hour care and pretty much 2 of us the whole time". They also spoke about their grief: Olive's daughter stated: "Every little change along the way was a step of grieving, by the time that he died . . . we just went yes, thank you; because it was over . . . it was more of a time of rejoicing when he actually went". Olive said: "I miss him but I wouldn't want him back in that way . . . there is a certain joy in knowing where he is".

Themes and Interpretation

Within this section the context of the informal caregiving experience is described and discussed in terms of the perception of time and space during caregiving. The informal caregiving experience, consisting of the themes of love, suffering, and transformation, is then explained. Each theme is expounded upon and interpreted in relation to the relevant literature. Finally the meaning embedded within the informal caregiving experience is explicated.

Caregiving Context

The final weeks of caregiving were intense and required the most from the participants. When the interviews were done the participants stated that the last few weeks were a short period of caregiving time but they also stated that during that time it seemed very long. Therefore, their subjective perception of time was altered during the caregiving period. The caregiving period was described as a short, intense, focused, and enclosed time during which the participants were totally involved with their loved ones, caregiving, and were constantly on the go.

During the analysis I was reflecting on my perceptions and feelings of the final weeks of my mother's illness. I could totally identify with the perceptions of the study participants. For me, the final weeks of my mother's illness were intense, vague and a long few weeks. It also seemed like a special and boundaried episode outside my normal life. I had to ask myself if my perceptions and analysis were such due to my personal experience. However, the participants' statements were clear about their perceptions and the primary research had also identified this phenomenon. The sections below describe the participants' involvement with

their situation and their perceptions of time and space within the caregiving context. This is followed by a discussion on the caregiving context.

Caregiver Involvement

Study participants were totally involved in caregiving during the last few weeks. Caregiving was perceived as an intense and focused epoch during which caregivers lived minute by minute, in constant attendance, with almost no breaks or getting away from caregiving, nor wanting to.

> ***Betty:*** Those months were lived for that second, you never thought the minute after the next second. You know it was very pure in a way, it was very focused and it was very living for exactly that moment.
>
> ***Irene:*** You just never get away from it no matter what it is you think you are doing, you might read a book, you might crochet, you might watch a TV show, but you are not really away from it cause your mind is still with it.

Perception of Space

Study participants felt that they had an intense connection with their loved ones plus other caregivers. They described this as an enclosed boundaried space where mostly only the caregivers and their loved ones existed or sometimes it included other close caregivers and family members. The rest of the world was perceived as existing outside this environment.

Betty: It was just like this really intense connection with everybody. We all had a goal, we all had a project, we all knew what we needed to do and it worked.

Olive's Daughter: It's just such a funny period of time. It's just like you're just closed in; you're such a family unit. People are coming into it or whatever. But you're so closed in as a family.

Perception of Time

The caregiving situation as well as the time period of the final weeks of caregiving were perceived almost as an unrealistic period of time which felt very different then and now (during the interview time). Participants found it difficult to remember and describe their subjective perception of time other than that it felt long then; and now, upon reflection it seemed to be short. Some participants also described their state as being constantly on the go, and doing what had to be done.

Irene: When I think about it now I think I lived in limbo. Some sort of a, I don't know, seems almost unreal. . . . It was only 2 months, just over 2 months. At the time it seemed like forever, like this was your life and there was no beginning or no ending to it. But when you think back on it, it was really a very short time.

Olive: When I look back on it now, I don't know how I did what I did. But you are just given, like I think you don't get, you don't save up that strength but its there to draw on as you need it. . . . You go on your adrenaline or something and I really don't know how I went through what I did.

Discussion on the Caregiving Context

The caregiving period was considered to be a critical and transitional period of time for the caregivers. Transitions refer to discrete, bounded duration of changes in status usually with long term outcomes (George, 1993). Bridges (2001) considered transition as the way we came to terms with change; without a transition change was considered to be superficial and empty, that is, it did not work. A transition could be triggered by a specific external event or change and consisted of three phases; an ending where the old ways of being would be released, a neutral zone which was the in-between period of confusion, and a beginning or acceptance of the new reality (Bridges, 2001). The study participants were considered to be in transition as they were dealing with changes triggered by the illness, caregiving, and the terminal state of their loved ones.

The perception of time during caregiving and at the interview time was altered. Time is usually conceptualised in two ways; objective time is the external calculated time of physics involving speed and duration or the clock time measured by watches, calendars, and the solar or lunar cycles; it is linear with each moment a discrete independent unit. Subjective time is the internal time experienced by individuals or personal time, and is based on the individual's involvement with the past, present, and future; as these are perceived as interrelated and integrated and not as independent succeeding moments (Polk, 1986; Sanders, 1986; Strumpf, 1987). Research by Martin (1986) on the experience of time revealed that clock time had a powerful influence on individuals yet individuals also had a personal experience of time whereby they

felt that their time was different from the time of others. The author stated that the individuals felt that the rate at which time passed for them depended on their circumstances. Time was perceived to pass faster when they were enjoying themselves and slowed down in difficult situations such as stress and uncertainty.

Study participants perceived caregiving as intense and involved; they were focused on their loved ones to the exclusion of all else; within this the perception of time and space was altered. The participants' world revolved around their loved ones and others existed outside it; there were clear boundaries between the insiders and outsiders. In other words the participants' sense of space had narrowed down to their loved ones and time was perceived as long and never-ending. Study participants were aware of the external time during the interviews when they were talking about their experience yet their subjective experience of time was that they were within the caregiving period for a long time; as noted above the subjective experience of time depends on ones circumstances. My sense was that when the participants spoke about their caregiving they perceived it as being out of this place or as existing outside their normal life.

Caregiving Experience

The caregiving experience was looked upon positively and was an experience that the participants would not have liked to forego. Study participants were grateful to have had the opportunity to be with their loved ones at home during this terminal period. The three major themes within this experience were love, suffering and transformation. Love consisted of the strong connection felt with their loved ones and included identification with their loved ones and a

feeling of their presence after death. Love was also expressed in wanting to be with their loved ones and in the feeling that they had done their best for them. The commitment felt to their loved ones, the open communication, and admiration of their loved ones were all part of the theme of love. Suffering resulted mainly from watching their loved ones suffer due to the disease process. Living with the terminal illness and dying as well as the memories of the terminal period were all part of the suffering experienced. Transformation was noted in the participants' expressions of the changes that had happened to them during the caregiving and post death period. These were an unfolding of themselves, changes in their inter-personal relations and changes in their thoughts, perceptions, and attitudes. Each theme is described and discussed separately in the following sections.

Love

Love, a feeling of connection with their loved ones plus concern and caring for them was the major theme in the interviews. It was the predominant experience for the participants and was the main factor behind their positive expressions of this critical period of their life. Study participants considered this time as a special and satisfying time of their life. Love was also the reason why they chose to provide care at home to their loved ones; it was what motivated them to provide the care at home even though at times it was difficult as noted in the theme of suffering. My initial analysis revealed a compelling positive emotion in the interviews; the study participants manifested an overall sense of contentment and happiness at having had the opportunity to be present for/with their loved ones. The participants expressed their positive feelings for/towards

their loved ones by using words such as 'love', 'bond', 'connection', 'being there', 'happy to provide care'.

Though I recognized the positive emotion expressed as the love that the participants felt for their loved ones, I was hesitant to use the word 'love' to refer to what I saw in the interviews. Upon reflection, I realised that this was due to my discomfort with the word 'love' and the use of it in our daily life to refer to everything and anything; for example 'I love my work', 'I love ice cream', 'I love so and so'. I felt it was a strong word that expressed the totality of the caregivers' positive experience during the caregiving period. However, I felt that using it to identify what I saw was not appropriate and could be misleading. When one talks of 'love' what might come to mind is romantic, passionate love between two people. What I saw was the depth and power of love or the devotion for another human being as the caregivers were children, partners, siblings, and even a daughter-in-law. Other words such as 'commitment', 'responsibility', 'closeness' were not enough to explain the total phenomenon I observed; though these were part of the experience.

I read briefly on love and discussed the issue with my thesis supervisor. I finally decided that the word 'love' best identified what I observed in the data. I felt that what I noted in the data were the manifestations of love by the caregivers; therefore, I questioned myself as to what were the expressions of love. The expressions were the positive feelings that caregivers talked about with regards to their caregiving experience. These were connection, togetherness, caring,

commitment, communication, and respect/admiration. I will elaborate on each of these dimensions with statements from the interviews.

Connection.

Love was seen in the participants expressions of the connection felt with their loved ones; in the self-identification felt with their loved ones; and in the feeling of the presence of their loved one at home after the death. Participants talked about the special bond/connection they had with their loved ones and that it became stronger during caregiving.

> ***Betty:*** I had a very unique connection with my mother too. I realised that that it was a very rare kind of relationship, very, soul mates you know. . . . We always had a very strong connection.
>
> ***Gina:*** I think if he had just been in the hospital and died in the hospital there wouldn't have been that bond. I mean I always had a bond with my dad, but it became stronger, different.

Participants expressed their connection when they talked about identifying closely with their loved ones in the sense that their feelings were related to the feelings of their loved ones. In other words, how the participants felt during the caregiving period related closely to how their loved ones were doing and feeling while meeting the needs of their loved ones was like meeting their own needs.

> ***Erin:*** I could feel what she felt. And like I say we thought alike I mean we really understood each other's needs. . . . I don't know where it came from . . . it was just there, part of loving.

> ***Lily:*** Whatever was fun for her was fun for me. So it wasn't like her needs and my needs were totally separate. . . . If I could organise a fun time [for S] with people, I was enjoying it too. . . . Certainly if S was having good days, I was having good days.

The interviews were done after the caregiving period; therefore, the participants also spoke about the connection with their loved ones after the death of the person. This connection was manifested in the participants' statements of the feelings of a presence of their loved ones around them. Participants' spoke of this even thought the issue was not directly approached during the interviews.

> ***Anne:*** I found the presence in the house. D's still here but he's not alive but there is a presence. . . . He's very much around and yet he isn't real.
>
> ***Gina:*** I couldn't sleep and I was just feeling really weird and so I sat into his armchair. . . . No one else ever sat in there; it was his chair. I sat in his empty chair and I swear someone came and hugged me and held me.

Togetherness.

The second manifestation of love noted in the interviews was the dimension of togetherness or closeness and sharing. All participants, most of them in both interviews expressed their wishes of wanting to be with their loved ones. They valued the time they could spend together with their loved ones or just be present for them. This seemed to be an internal self-need that the participants needed to fulfil above all else; nothing else mattered.

Erin: I think I was just greedy for every minute of time. I think that was a large part of it with her. I didn't want to miss a minute.

Fran: I couldn't wait to get back home. . . . It's like wow; we didn't spent enough time together. . . . Here I felt I was needed and to go into town was really an awful waste of time.

Irene: As far as feeling like I had to get away and it would feel good if I got away. Even in my mind, my mind didn't want to go away either; I think I just wanted, we knew he had a short time and I wanted to be with him as much of that time as I could.

Caring.

The third dimension of love was that of caring for their loved ones or what the caregivers expressed as 'happy to do it'. Participants expressed happiness at being able to do the caregiving, and felt satisfied that they had done their best for their loved ones. Study participants wanted to and appreciated the opportunity to care for their loved ones. They were glad that they could do it, would do it again, and felt positive about the caregiving experience.

Betty: I just felt that it was such a privilege to be the caregiver . . . I just feel that so strongly.

Erin: I was just so happy to do it [caregiving]. I really, really loved her. . . . It was a gift for me to be able to do it for her because I really loved her.

Harry: You don't do it [caregiving] because you've got to do it; you do it because; well, you want to do it.

The interviews were done after the death of the loved one; therefore, the caring dimension was also expressed in terms of the participants reflecting on their caregiving experience and expressing satisfaction at having been able to provide care at home. Research participants stated that they felt they did their best and had no guilt feelings or regrets when reflecting on their caregiving experience. Participants reported that they would have had regrets if they had not been able to provide the care at home.

> ***Betty:*** There isn't one thing that I regret in terms of the caregiving and I think if we put her in the hospital or if we did the traditional route I think I would have had regrets.
>
> ***Nina:*** The feeling that I had done everything I could . . . I felt that it was a positive thing in the fact that I had done everything that was possible on my part.

Commitment.

Study participants felt a deep sense of commitment to their loved ones and deemed it their responsibility to provide the best care they could. Their own needs were regarded as secondary to the needs of their loved ones.

> ***Colin:*** You have a duty, it's not as harsh as that; it's just because you want to, you want to do it so you do it the best you can.
>
> ***Lily:*** I think there are times when I could just be really intense about doing something and just really put out 200 per cent and then the time comes later for me to take care of myself. And I think that's how I saw it with S.

Communication.

Openness and honest communication between the caregivers and their loved ones was appreciated and treasured by the study participants. This was a mark of their close relationship, which became stronger during the caregiving period and assisted in the parting.

> ***Kim:*** We talked a lot, when T would go out he would sit here and he'd talk about all kinds of things. Like, where do we get buried? I never even thought of it. . . . If something would have happened fast I wouldn't have known nothing.
>
> ***Olive:*** He knew for quite a while, we always talked about it [cancer]. When he first got sick we said were going to talk about this . . . we were always open about it.

Respect and admiration.

Respect and admiration for their loved ones was noted in the emotional tone of the interviews and the verbal statements. Participants expressed their respect and high regard for their loved ones when they talked about their caregiving experience.

> ***Betty:*** She died with such dignity and such grace and that was the type of woman she was, and just to see that was a real learning experience.
>
> ***Kim:*** You sure gain a lot of respect for him because of the way he did it. He never complained. . . . The respect of him trying so hard, and right from the time he was told, he looked at me and said;

there are so many things I still want to do. And he kept working towards them. . . . He never gave up. So he gained very much respect for him.

Discussion on Love

While I was reflecting on the themes I was also exploring the issue of love in literature, especially in psychology. Love is a topic that is discussed in almost all types of literature from imaginative narratives, poetry, and arts to philosophy and psychology. I got involved in the subject; and it took me some time to get back to my research. I realized that to understand love as a lay person and to study love as a subject/concept were two separate issues; until now I had understood love as a lay person and I saw it in a manner similar to the caregivers. For me, love was the ultimate expression of ones' feeling for another; it is experienced as a positive emotion that bestows a deep sense of happiness/bliss; it provides meaning and purpose in life. Reading the literature put me in a dilemma: What was love? What kind of love – as mostly love was discussed as types of love – was I seeing? Was it eros, storge, or agape; companionate or passionate love?

The Webster's dictionary (1989) gives a number of definitions for the word love; everything from a strong liking for something to deep affection for someone. For the Greeks love had many forms such as; eros (romantic), storge (family), philia (friendship), agape (altruistic). Levy (1979) discussed the definition of love in Plato's symposium and stated that to understand love as a vision of absolute beauty one needed to progress from love of physical beauty in an individual to love of all physical beauty; and then, love of beauty in a soul lead

to awareness of beauty in activities, institutions, and sciences. Hazo (1967) suggested four characteristics common to most conceptions of love; these were; it implied interest, involved preference, inclined towards action and was good or productive of good. These for him formed the core of the idea of love. The dictionary definition was too broad; the philosophical discussions on love were too abstract; I was not able to relate that to what I saw in my data; I continued to explore other literature on love especially the psychological literature.

Kovecses (1986, 1991) explored the concept of love from a linguistic perspective. The author utilised metaphors, metonymies, related concepts and cognitive models to describe love; however, his discussion was limited to the study of romantic love. The author considered love to have some features that were necessary while others that were typical and stated that love was multifaceted. That is, it comprised of beliefs, attitudes, desires, feelings, cognitions, behaviours, and physiological responses. Psychologists who regard love as an emotional concept have studied it from a classical or prototype approach (Johnson-Laird & Oatley, 1989; Russell, 1991; Shaver & Hazan, 1988; Shaver, Morgan & Wu, 1996; Shaver, Schwartz, Kirson & O'Connor, 1987). The authors considered love as a basic emotion that did not have sharp boundaries. Love consisted of a "complex tendency to think and act in certain ways towards another person" (Shaver & Hazan, 1988, p. 477). Shaver et al. (1996) determined love to be a set of emotions related to the three interrelated behavioural systems of attachment, caregiving and sex.

According to Fromm (1956) "love is an active power in man; a power which breaks through the walls which separate man from his fellow men, which unites him with others; love makes him overcome the sense of isolation and separateness, yet it permits him to be himself, to retain his integrity" (p. 20-21). The active character of love was described as "love is primarily giving, not receiving" (Fromm, 1956, p. 22); the giving was the giving of oneself to another so that the other was enriched, this in turn enriched oneself. Fromm (1956) identified other interdependent elements of love: care was the active concern for the life and growth of the other; responsibility was the voluntary response to the un/expressed needs of another; respect was the ability to see a person as he was, be aware of his unique individuality; knowledge consisted of a deep knowing of the other achieved by the experience of union/fusion with another.

Lewis (1960) discussed four kinds of love: affection was the most diffuse and humble type of love and was present within the family environment; friendship was the connection between friends and evolved from companionship; eros was the love between the lover and beloved and included sexual desire; love of god and people was the last love discussed. Love was thought of as an attitude held towards a person that made one think, feel, and act in certain ways towards that person; it was comprised of caring, intimacy, and attachment (Rubin, 1970, 1973). Lee (1977) discussed the styles of love using the analogy of colours; primary colours/styles – eros (passionate), ludus (game-playing), storge (friendship); and secondary colours/styles – agape (altruistic), mania (possessive), pragma (logical) – which occurred from various combinations of the primary

styles. For example a mixture of eros and storge yields agape. Hatfield and Walster (1978) spoke of two basic types of love; passionate love was an intense longing for union with another and companionate love consisted of affection for those with whom one was connected. Were the types and styles of love one and the same thing? I could see similarities between the various descriptions of love and my data even though most studies were done from the perspective of romantic love. The literature provided me with an understanding of love yet I was not clear about love or its constituents.

Sternberg and Grajek (1984) stated that the structure of love was similar across the various relationships one had and that it consisted of a general factor of interpersonal communication, sharing, and support. Aspects of this general factor were; deep understanding of the other, sharing of ideas, information, and feelings, emotional support and affection to each other, and helping and needing each other. Sternberg (1986) in his triangular theory of love identified three components of love. Intimacy was feelings of caring, support and involvement with the other; passion was the psycho-physiological arousal brought on by the other; and commitment was a cognitive decision made that one loved the other and would stay in the relationship.

Swensen (1972) studied the behaviour of love; that is the ways in which people expressed their love for each other. According to the author love was expressed in several ways. 1) Material (gift exchange) expressions occurred mostly within families. 2) Nonmaterial expressions consisting of support, encouragement, interest, and respect occurred generally in all relationships. 3)

Verbal expressions of love occurred mostly between peers (brothers, sisters, spouses, friends). 4) Physical expressions were largely confined to opposite sex relationships. 5) Tolerance of unpleasant aspects of the loved ones also occurred generally in all relationships. 6) The last behaviour was unexpressed feelings of love whereby love for the other person was not revealed; this was found mostly with regards to love for ones mother and close person of opposite sex.

Studies done by Fehr (1988, 1994), and Fehr and Russell (1991) on the concept of love revealed that friendship love and familial love was closest to lay people's concept of love. The authors noted that men and women had the same concept of love although they could vary in their beliefs and experience of love; people could use and understand the concept of love without knowing necessary and sufficient features for it and; and the most common attributes of love were caring, helping, connection, sharing, open communication, understanding, respect, and closeness. The authors concluded that the folk definition of love was complex; there were no clear boundaries between love and other related experiences, and it was more encompassing than the psychologists' typologies; that is, it focused on all forms of love between family members, not just romantic love. According to Fehr (1988, 1994), the companionate type of love was at the core of what the term 'love' meant to lay people and it included features such as caring, friendship, trust, respect, honesty.

The exploration of literature enriched my understanding of love; I could identify various aspects in the literature on love within the data yet it was not sufficient and no one explanation was adequate to illustrate what I observed in the

data. I went back to my data and had another look at it. What exactly was I seeing? How was love manifested by the caregivers? Studies done by Fehr and Russell (1991) had specifically identified connection or bond as one of the attributes of love while deep understanding of the loved ones was noted by them as well as by Sternberg and Grajek (1984). Hatfield and Walster (1978) discussed the connection with loved ones in their explanation of companionate love while Fromm (1956) spoke of connecting with another to know another. The research participants clearly manifested this dimension of love in the interviews; it was evident during both the caregiving and the post death period although in different forms. Participants also spoke of the connection becoming stronger during the caregiving time and that they became more aware of it.

Closeness and sharing were identified as attributes of love (Fehr & Russell, 1991), or aspects of the main factor of love (Sternberg & Grajek, 1984; Sternberg, 1986). Fromm (1956) referred to this when he talked of uniting with the other. The statements of the study participants within the dimension of togetherness reflected this aspect of closeness. Fromm (1956) identified care or concern for another as an element of love; caring and helping were also considered attributes of love (Fehr & Russell, 1991; Sternberg & Grajek, 1984; Sternberg, 1986). Within the data these were present under the caring aspect. The dimension of commitment which consisted of a cognitive decision to be with the loved ones was observed in the data as well. Sternberg (1986) had identified commitment as one of the three components of his triangular theory of love. Fromm (1956) described commitment as responsibility in that it was a voluntary

response to the expressed or unexpressed needs of another. Open communication was identified as an aspect of love in the above literature (Fehr & Russell, 1991; Sternberg & Grajek, 1984) and in the data. The last dimension of love noted in the data was of respect for the other or the ability to see the other as a unique individual. This was noted in the literature as an element of love as well (Fromm, 1956; Fehr & Russell, 1991).

This review shows that a precise accepted definition of love does not exist. However, love is known and recognised by people when they see it. The aspects of love manifested in the data such as connection, togetherness, caring, open communication, commitment, and respect/admiration for their loved ones were identified by lay people as attributes of love (Fehr & Russell, 1991). Fehr (1988, 1994) noted that lay peoples' concept of love was similar to what Hatfield and Walster (1978) described as companionate love; "the affection we feel for those with whom our lives are deeply entwined" (p. 9). The expressions of love observed in the data were closest to the description of companionate love and the concept of love as described by Fehr (1988, 1994).

Suffering

Listening to the interview tapes and reading the transcripts was difficult as I could hear and see in them the deep sense of sorrow and distress that the participants went through during the caregiving/post death period. I was not sure what to call this feeling that came across so strongly to me. Initially I felt it was the grief and sorrow that the participants felt at the loss of their loved ones. As I continued to listen, I felt that what I was hearing was the distress they felt during

the whole process of terminal cancer caregiving and not just the sense of loss of their loved ones. What was it? Was it emotional or psychological pain? I felt that the word 'pain' did not sufficiently explain what I was hearing, as pain is usually used to refer to physical pain and emotional or psychological pain tends to be associated with a psychiatric or psychological problem such as depression or anxiety. I felt that the process that the participants were expressing was a normal one for them; not one that they or I could label as abnormal. The word 'pain' did not express the totality of what I could see and it seemed to imply that the participants had emotional/psychological problems.

The word 'suffering' was used by the participants to describe the state of their loved ones. Reflecting on this and my experience of my mother's death, I realised that what I had experienced and what the participants expressed was the suffering that they went through during the caregiving/post death period. I felt that the term 'suffering' best described a natural process that the participants went through while providing palliative care to their loved ones during the terminal cancer and after death. In most cases the suffering started from the time of cancer diagnosis and continued on after death; however, it was more intense during the last few weeks/months of caregiving. Study participants expressed three main aspects with regards to suffering; watching their loved ones suffer due to the illness process, living within the caregiving situation, and post death memories of the distress of their loved ones. These dimensions will be described below using statements from the interviews.

Watching.

The word 'watching' jumped out in all the statements made by the participants. Watching their loved ones suffer due to the disease process caused intense distress to the caregivers. Generally, suffering was considered as just watching their loved ones suffer, or in many cases it related to three specific areas. These were watching their loved ones go through the psychological losses, watching them physically deteriorate, and watching them have pain. Participants explicitly verbalised watching the suffering of their loved ones as the major difficulty faced during the caregiving period.

Dave: Strictly just watching her [caused the most difficulty].

Erin: Watching her, especially how it was affecting her, how all the things . . . she was loosing was affecting her; her independence, her dignity, her privacy, her control, that was the hardest thing. . . . It was her losses, exactly, that's hardship, her losses; that was the hardest thing for me . . . . For me and mom in the situation the most stressful I would say was watching her go through the losses. That was the worst.

Colin: You could tell she was in pain. That shouldn't be. There is just no reason for it. There's nothing, getting rid of the pain is not going to affect her death, it's going to happen. It would make me mad and there was not a darn thing I could do about it.

Dave: Watching her go downhill and it took years to go downhill . . . . How her body was going downhill and how it changed from a

70-year-old to an 80-year-old to a 90-year-old. Then I felt so badly about it. . . . Watching this and thinking what is causing it . . . . Just watching her deteriorate.

Living.

Suffering was related to the day to day frustrations of organising and managing the caregiving and other issues of life that needed attention. Study participants expressed a sense of wanting to stay focused on their loved ones; therefore, other issues were considered to be intrusive. This was particularly distressing to the participants during the last few months as in many cases there was not much that they could do for their loved ones who were dying. Participants made statements that pointed to the multiple emotions experienced such as helplessness and uncertainty as well as their interactions with the healthcare system particularly if these were of a demanding rather than supportive nature.

Colin: It was frustrating for us because things weren't being done or things were changing and we didn't know why. We're doing the medication, we're doing this, we're doing that. Why isn't, why is she fading? Why is she still in pain?

Dave: The last nights were frustrating; I wanted to be awfully close to her because she was having awful trouble with pains in her hand and all. . . . But I could hardly hold her hand because you had to be so careful that you didn't hurt her arm.

Fran: He really was supposed to drink all this water every day and that was really difficult for him and that was kind of stressful to try and get him to do something that he didn't really want to do.

Gina: So I had to take my father to the physician's office so she could say oh yeah, he's short of breath he needs oxygen. I mean it was a cruel, cruel thing to do.

Lily: there just seems to be no place to go to get information . . . I didn't know where to go. Plus I didn't have the time to be running around trying to find places and to connect, or to make appointments.

Mary: I was very guilt ridden because I had to leave mom to spend time with my kids. I was very angry at my kids because they took that time away that I could've spent with mom.

Memories.

The memories and images of the suffering of their loved ones, being there, and watching it, caused suffering during the post death period as well. For most participants the memories were identified as causing suffering not only in the first interviews but also during the second interviews which were about ten months after the death of their loved ones. Study participants vividly remembered the suffering and the images of their loved ones during the last months of caregiving.

Dave: One of the worst thing is I picture her in all these different stages of suffering but I can't picture her in her wholeness; five years before.

> ***Kim's daughter:*** That's the worst part of care giving . . . . It's the memories of the things he went through and having him suffer that badly. That's the worst.

Discussion on Suffering

These descriptions illustrate the participants' experience of suffering during the terminal caregiving period. What is suffering? The Webster's (1989) dictionary defines it as to undergo or endure pain, distress, injury, loss, or anything unpleasant. Within the healthcare literature the term suffering appeared as a search heading from 1990 onwards. Prior to this pain/psychological factors were used as search headings (Rodgers & Cowles, 1997). Some authors suggest that health professionals are reluctant to address suffering or topics such as death directly as these are connected to ones own existence and once acknowledged become a personal threat (Copp, 1990; Rodgers & Cowles, 1997).

According to Kahn and Steeves (1986), suffering differed from pain, could be induced by factors other than pain, and was not clearly defined as a concept. They defined suffering as "an individual's experience of threat to self and is a meaning given to events such as pain or loss" (p. 623). Cassell (1991) considered suffering as "the distress brought about by the actual or perceived impending threat to the integrity or continued existence of the whole person" (p. 24). A conceptual analysis on suffering by Rodgers and Cowles, (1997) defined suffering as "an individualized, subjective, and complex experience that involves the assignment of an intensely negative meaning to an event or a perceived threat" (p. 1048). This literature addressed the concept of suffering from the perspective of a

patient and/or health professional not that of the informal caregiver. According to Hinds (1992), the phenomenon of suffering has been addressed primarily within the context of the pain and suffering of patients; the notion of the family caregivers' suffering has hardly been addressed. Reflecting on these definitions and my data, I saw that although the participants did not define their situation in terms of suffering, their verbal responses and the emotional tone of the interviews gave evidence of their suffering. Based on what I heard and the literature, I considered suffering as a negative, natural, subjective, individual, and complex experience that the participants consciously experienced during their caregiving.

Suffering was negative because it caused distress, disharmony, and was undesirable. One of the defining characteristics of suffering was that it was an aversive experience (Cherny, Coyle, & Foley, 1994). Suffering was a natural process that the caregivers went through; it "is a common life experience encountered by every human being" (Travelbee, 1971, p. 61); it was intrinsic to human existence. "Suffering can be conceived as a natural phenomenon, as one phenomenon of human existence as a whole. . . . Suffering is part of human existence, like life and death. Its forms may vary, but it is an element of life" (Eriksson, 1992, p. 120). From what the study participants expressed, I could see that suffering was natural, as it was such an intrinsic aspect of the participants' life that they never mentioned it or labelled it as suffering; it was a natural part of the whole caregiving experience. Hinds (1992) also noted that the caregivers in her study expressed concern about their loved ones' suffering but did not use the term suffering to refer to their own situation.

Suffering was individual and subjective as it is difficult to measure or assess and can only be inferred (Rodgers & Cowles, 1997). Though caregiver suffering was heard in the interviews, it was not possible to measure it or assert that one caregiver suffered more than another. According to Moulyn (1982), people suffered in different modes which could not be compartmentalised and so could not be measured. Suffering also varied from person to person (Rodgers & Cowles, 1997). This was seen in the data in that different aspects of the caregiving situation caused more distress to different participants; for some it was watching the losses, for others it was the pain, while living within the terminal caregiving situation and attending to the day to day aspects of living caused distress to others. What I observed in the data was the expression of suffering by the participants; Kahn and Steeves (1995) stated that "the expression of suffering is more accessible to nurses than the experience [itself]" (p. 12). Based on these expressions I inferred that the participants suffered during the caregiving period.

Finally suffering was deemed to be a complex experience because it was multidimensional; there were at least two principal dimensions with other related dimensions within the caregiving situation that caused distress to the participants. Watching the suffering of their loved ones was one dimension of the experience. The participants were witness to the suffering of their loved ones. Witnessing a loved one suffer causes extreme angst in the caregiver, especially when they witness the trajectory of dying where the symptoms are not well managed (Gregory & English, 1994). Suffering was viewed as a phenomenon that was based on the affective response of the sufferer and the caregiver, who shared in

the individual's suffering empathetically (Wilson, Balszer, & Nashold 1976). The Latin roots of the word suffer means 'to bear' (Rodgers & Cowles, 1997). I noted that this was exactly what the participants were doing when they stated that watching their loved ones suffer was the most difficult for them. They were empathetically participating in the suffering of their loved ones and 'bearing it'. Suffering was evident in the post death period in the form of memories of watching their loved ones suffer and the intense images of suffering that the participants could vividly recall.

The second dimension of the experience of suffering was related to dealing with life and the caregiving issues on a day to day basis. For the participants this involved dealing with the healthcare system, their own emotions and reactions to the situation, and the feelings of helplessness associated with the care of their loved ones. Hinds (1992) identified a number of caregiver emotions such as guilt, feelings of uncertainty and helplessness that were part of the suffering of caregivers of cancer patients. Other factors identified as contributing to suffering in the caregivers of cancer patients included distress related to transactions with health care services (Cherny et al., 1994). All these were noted in the interviews as expressed above.

Literature on suffering indicated that an awareness of our humanness was an important component of suffering. People required a cognitive and emotional awareness of their individual completeness as people for suffering to occur (Rodgers & Cowles, 1997). An individual had to perceive and appraise a situation as distressing and have conscious awareness of it in order to suffer; there had to

be a sense of past/future and aim/purpose in life (Cassell, 1982, 1991; Cherny et al., 1994; Lindholm & Eriksson, 1993; Steeves & Kahn, 1986; Travelbee, 1971). This was observed in the data as well; the study participants consciously suffered during the terminal cancer caregiving period. However, they did not label their experience as suffering.

Transformation

As I remained immersed in the data, I began to see that the participants were talking of a profound experience that they had undergone. What came out to me was a sense of them feeling that that they had gone through something that had in some ways left a mark on them. Initially I was not able to name what I observed in the data; I felt its subtle presence but could not see anything concrete that I could talk about. Sustained engagement with the data made me realise that the participants were talking of the deep impression that the terminal caregiving period had left on them. The experience had in some ways changed them.

What was this change that I observed in the data? I could see that the caregiving period was a critical time for the participants and it would leave some marks on them. However, I felt that what I was hearing them say was not changes such as coping with the various aspects of caregiving from physical care to resource management though these issues were present. What I heard was some deep subtle change. Study participants felt that the caregiving and post death period had an impact on them in that they felt changed now as compared to before these events. What was this change? We know that people undergo significant personal changes as part of the growth process in life and during critical episodes

in their lives. In literature these deep changes have been referred to as transformation or transcendence.

The interviews had not explored the issue of transformation/transcendence directly yet it was present in the participants' responses; since it was not discussed in depth its presence remained subtle. At this point, I acutely felt the limitations of doing a secondary data analysis as I could not explore this dimension of the caregiving experience in depth with the participants. The transcripts revealed statements about the changes experienced by the caregivers though there were no drastic overnight transformations. I felt that what I was seeing was the process of transformation that the participants had been going through.

Transformation was not uniformly present in all interviews as being at the same stage; some participants had consciously gone or not gone through it and life went on though it was subtly different that before; some participants were still going through the process and were reflecting on issues; other participants were still grieving acutely and were not able to look beyond missing their loved ones. They felt that they did not belong to the world and life felt empty. It was noted that for most participants the aspect of transformation was related to their reflections on caregiving; those who had reflected on their caregiving experience were able to see beyond it while others did not want to go into it as it was too painful to think about. The main areas where transformation was noted were within the participants themselves or self-discovery; changes in their interpersonal relationships; and alterations in their thoughts and perceptions. These areas are described and illustrated below with statements from the participants.

Self discovery.

Study participants talked about discovering themselves, the three main areas within this were that caregivers discovered their own inner capacity, their personal growth and their expression of themselves. Participants stated that they had found within themselves an inner strength and capacity during the caregiving period that they were not aware of; they stated that they found strength within themselves when they needed it. They also spoke of inner growth and being able to express their own personal individuality.

> ***Fran:*** Its [caregiving experience] made me realise that I'm very strong, a lot stronger than I ever; I never thought I was weak but I certainly didn't think I was that strong.
>
> ***Betty:*** I think the last job is trying to struggle with my own spirituality and try to figure out where is she in this world and I'm still doing that. . . . It's a real learning experience; I've learned a whole bunch about myself in the last year . . . . So there is that search right now.
>
> ***Nina:*** The Advent candle and the Crèche and the Arabian star and a few things around which probably wouldn't have been here last year . . . because I didn't want to push . . . my feelings [religious beliefs] on to him. So I feel quite free that I can do that this year. . . . Absolutely, I know I am [becoming her own person]; I know I've changed . . . . I feel very positive about it.

Interpersonal relation.

Study participants stated that their relationships with other family members and friends had changed. This ranged from the bonds between the family members becoming stronger to the opposite; whereby they became worse than what they were before the illness and caregiving.

> ***Betty:*** You can't go through an experience like that and not have your relationship change. . . . They [caregiving team] went through it from day one until the end and the connection will always be different with those people.
>
> ***Betty:*** Through crisis everything is exaggerated. . . . J my sister . . . we've always been very close so we just got a whole bunch closer. And my father and I have had issues, so our issues got so much bigger . . . . It's changed the family dynamics totally . . . . So the relationships have changed . . . some for the better and some for the worse.

Thought and perception.

Study participants talked about changes in their thoughts and perceptions of events, things, and issues. They stated that they reflected on disease and death issues much more now than before the caregiving experience.

> ***Erin:*** I gained a whole new understanding how some families would not be able to do it [caregiving]. To take care of their loved one in their home, it would just not work, where others would just naturally be fine. But I started thinking about that a lot.

> ***Fran:*** I would want to live in Sweden or one of those places where you could actually make your own choice. . . . That quality of life is certainly not something I would want. . . . I really didn't have a whole lot of thoughts of this before so that certainly gave me food for thought.

Discussion on Transformation

As I was discerning this theme and trying to put into words what I sensed in the data, I also appraised the literature on transformation and transcendence. The Webster's (1989) dictionary defined transformation as a process of change in form, appearance, nature, or character while transcendence was defined as going beyond or above the limits. Personal transformation was defined as a "state of being conscious of one's consciousness" (Ferguson, 1980, p. 68). Transformation was considered to be an evolutionary process (Ferguson, 1980); therefore, it was ongoing, occurred over time, and enabled individuals to achieve a clearer and expanded vision of the world with each episode opening wider and higher horizons for the person. Transformation consisted of profound changes in one's perceptions of reality; it was a circular, spiral process that involved self-reflection and the adoption of new and broader self-definitions which lead to an expanded state of consciousness (Wade, 1998).

A concept analysis by Wade (1998) defined personal transformation as "a dynamic, uniquely individualised process of expanding consciousness whereby individuals become critically aware of old and new self-views and choose to integrate these views into a new self-definition" (p. 713). According to Wade

(1998) transformation was a journey without a final destination. It was preceded by an event that disrupted one's life such as some stressful life experience (in the present case this was the terminal cancer caregiving). The event produced an opportunity for reflection and expansion of consciousness. Extreme pain or anxiety could prevent an individual from raising to the challenge in which case transformation might not occur (this was seen in some participants who were still in acute grief and unable to reflect on their experience). This way of dealing with challenge has been referred to as 'numbing'; that is, sealing off the experience (Jaffe, 1985). Transformation occurs when individuals choose to face the issue and reflect on it; they then interpret their experiences in a new context and their self-view changes. The personality expands to accommodate the new experience and new levels of capacity and awareness develop (Jaffe, 1985); this growth was expressed by some participants. People who have experienced transformation have expressed changes in their personal self and personal relationships (Jaffe, 1985); this was observed in the data as well.

What is transcendence? It is the capacity to reach beyond oneself; to extend oneself beyond personal concerns and develop a broad perspective on life which in turn leads to finding meaning in life? This explanation of transcendence was discussed from the humanistic, transpersonal, and existential psychology (Frankl, 1946/1984, 1966; Maslow, 1969; Yalom, 1980, 1982) as well as nursing (Coward, 1990; Parse, 1981; Reed, 1991, 1996) perspectives. Reed (1991) defined transcendence as "the expansion of one's conceptual boundaries inwardly through introspective activities, outwardly through concerns about others'

welfare, and temporally by integrating perceptions of one's past and future to enhance the present" (p. 5). Transcendence was regarded as the expansion of one's boundaries beyond the immediate constricted views of oneself and the world. Earlier developmental forms of the self that limit one's ability to integrate new life experiences are transcended (Reed, 1996). According to Hanna, Giordano, Dupuy, & Puhaka (1995), the psychological change associated with critical life events was developmental and therapeutic; and that it involved a "sense of moving beyond or stepping outside of a set of perceived restrictions, confines, or limitations" (p. 146).

According to Acton (2002) and Acton and Wright (2000), the stressful experience of family caregiving could provide caregivers with the incentive to self-transcendence as it provides opportunities for self-reflection (introspection). Acton and Wright (2000) described self-transcendence as the "ability to look beyond the self and present difficulties, to extend concern to others, and to find personal meaning and wholeness in the context of life-changing events" (p. 143). Transcendence was seen as related to health and healing and required effort to achieve but was also seen as a resource. It was individualised and affected by faith, culture, context, and personality.

Both negative and positive experiences could promote self-transcendence or the movement towards growth and development (Acton, 2002; Acton & Wright, 2000). Acton and Wright (2000) discussed the difficulty of achieving the intrapersonal, interpersonal and spiritual aspects of transcendence in the context of family caregiving to patients with dementia. The intrapersonal dimension

consisted of reflection and movement from self-absorption to an expanded view of life and peace. The interpersonal aspect related to the ability to reach out and connect with others. The spiritual component was the finding of meaning and growth in the situation. The study by Acton (2002) on transcendence in caregivers of patients with dementia revealed that the caregivers did not demonstrate evidence of self-transcendence. The author suggested that the caregivers could still be searching for meaning as self-transcendence required time and effort, a resource that may not have been available to the caregivers due to the stressful nature of caregiving to patients with dementia.

As seen from this discussion, there are similarities in the description of transformation and transcendence. Therefore, I will attend to both descriptions in the discussion of this theme. I re-examined the data in light of the above descriptions of transformation and transcendence. I could not say that what I saw was transformation or transcendence exactly as described above. The caregiving period was a stressful critical time for the participants. I observed that some participants had achieved personal growth and development during this time due to self reflection on themselves and their situation; others had sealed off the experience and were not ready to visit it. As noted before, transformation was seen as an ongoing process with participants situated at different points in the process. For some, life had gone on after having put the experience behind them. This happened either after self-reflection and transformation/transcendence or after sealing off the experience. For others transformation/transcendence had not

yet arrived as they were still in the beginning stages of reflection or had not yet started to reflect due to the freshness of the experience.

The aspects of transformation noted in the data reflected the intrapersonal, interpersonal, and spiritual dimensions of transcendence. Intrapersonal growth was noted in the participants' descriptions of self-discovery and in the changes in their thoughts and perceptions due to the process of reflection. This was seen as the inward expansion of one's boundaries and the temporal integration of perceptions. There was increased awareness of personal capacity and a broader view of life. Interpersonal development was noted in the participants' descriptions of the closeness achieved within the family and the appreciation of other family members by the primary caregiver. I considered this as an outward expansion of boundaries though it was not manifested in the manner defined by Reed (1991) which was more in the direction of altruism. Few participants spoke directly about the spiritual dimensions of transcendence; however, its presence was evident in their positive expressions and their satisfaction with regards to caregiving. It was also observed in the participants' references to a higher power/source of strength. In summary, transcendence/transformation was observed within the participants in that there was an expansion of their boundaries beyond the immediate constricted view of self and the world. That is, there was an expansion of consciousness whereby the participants become aware of their old and new self-views and integrated these views into their self-definition.

Caregiving Meaning

I contemplated on the overall caregiving situation and its perception by the participants as a critical transitional period of life. The participants perceived the terminal caregiving period as an intense enclosed space with distinct boundaries encompassing the immediate family, friends, caregivers. Outsiders came in and out of this space on and off depending on the situation at hand and the immediate issues that were being dealt with. For example, formal caregivers would enter the space when they came in for particular health related issues such as wound care; relatives and/or friends would enter the space when they came for visits and sometimes assisted in tasks such as shopping. During the caregiving period the participants' subjective perception of the passage of time was altered; they felt that time went by very slowly. Therefore, the last few weeks of caregiving seemed like months to years for them. During the interview, research participants were aware of this altered perception of time and referred to their perceptions of subjective time in relation to the objective or clock time. This was the context of caregiving or the context within which the caregiving experience was explored.

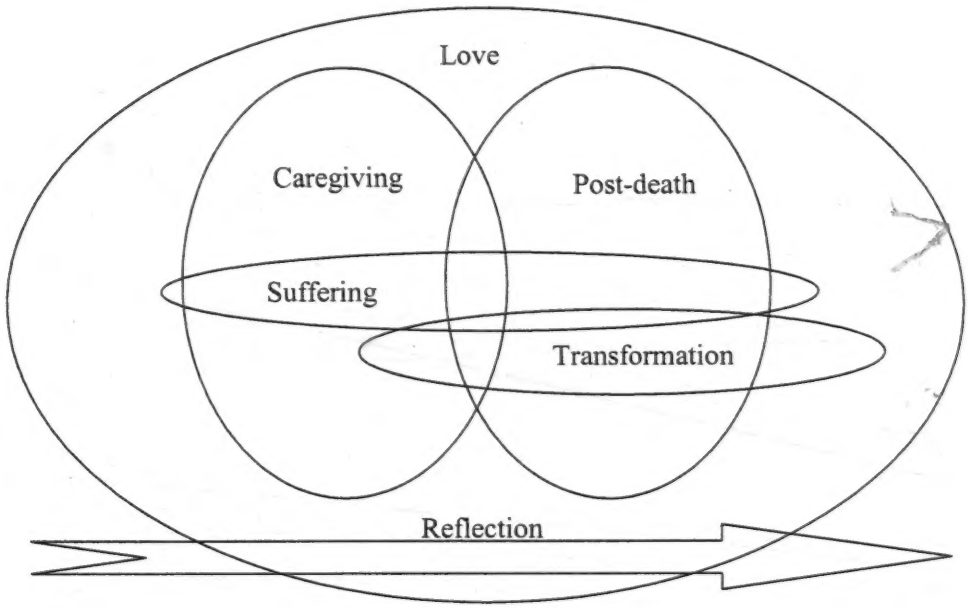
The caregiving experience consisted of the positive emotions of love and the negative feelings of suffering as well as transformation in self perception and the awareness of the world at large. Visualising the elements of the caregiving experience within the caregiving context as a whole; I pictured caregiving as a journey encompassed by love, which evolved from suffering to transformation within the caregiving and post death period. Figure 2 is a diagrammatic illustration of this process. The journey does not have clear margins or start and

end points in time but is a gradual and diffuse movement from one point to another. This movement is not linear but occurs in a circular manner; that is, caregivers may simultaneously be feeling all the elements of the experience or go back and forth from one to another; however, the movement has a forward drive to it. It does not follow the objective perception of time but is an inner movement that caregivers go through; that is, there are no definitive objective periods of time for the process, individuals go through it at their own time and pace.

This journey may start any time from the cancer diagnosis of the loved one to sometime before their death and may end some time after death. The study participants were at various points within this movement; some talked about the changes they had experienced while others spoke about their loved ones and personal suffering. Research participants decided to provide home-based care to their loved ones during terminal cancer primarily out of love (wanting to be together and present to their loved ones). Participants experienced suffering due to the suffering of their loved ones from the disease process and the day to day frustrations of living during this time. Transformation was the outcome of the process; participants felt that they had changed and grown during this time, their world view had changed as well.

Figure 2

Caregiving Experience and Meaning



The Caregiving experience is visualised as encompassed by the experiential theme of love; within this there is movement from the theme of suffering to transformation within the context of the caregiving and post death period. Meaning in caregiving is embedded within this caregiving experience.

Reflection is the critical circular process encompassed by love that begins primarily during suffering and its outcome is usually seen in the transformation experienced by the caregiver.

The caregiving experience within the caregiving context provided meaning for the study participants during and after the caregiving period. However, for the participants to consciously ascribe meanings to the caregiving they needed to make the journey described above; a process that required personal reflection by the participants on their overall caregiving experience. To reflect is to think, ponder or meditate (Webster's Dictionary 1989). Personal reflections are thoughts occurring to oneself upon contemplation of a situation, action etc. Reflection is a process through which people can dialogue with themselves resulting in increased self-awareness and self-discovery. Lauterbach and Becker (1996) described the process of self-reflection used to increase personal awareness and understanding as:

> A dynamic multidimensional human process represented by a ribbon turning and looping, bending back to the world of self and experience. As awareness is increased, the reflective ribbon continues its movement, changing and initiating reflective action. As reflection leads to greater awareness of meaning in experience, it leads to self-understanding (p. 61).

According to these authors, reflection enabled people to see their situations with new eyes. This could result in different interpretations of meaning and expanded awareness and consciousness.

Atkins and Murphy (1993) described reflection as a three stage process and identified the skills needed in each stage. First was the awareness of uncomfortable feelings and thoughts; for this one needed to be able to analyse

ones own feelings (self-awareness) and to recognise and recollect key features of the experience in order to describe it (description). Step two was critical analysis of the feelings and experiential knowledge; here one needed the skills of critical analysis so as to examine the components of the experience and explore alternatives. The last stage required one to have the skills of synthesis to integrate previous experience/knowledge with the present; and evaluation, which consisted of making judgements about the value of the experience in order to develop a new perspective. Based on the literature and observations made from the data I regarded reflection as a critical circular process that occurred during the caregiving and post death periods. It was encompassed by love, began primarily during suffering, and the outcome was perceived in the transformation.

The meaning in caregiving was embedded in the caregiving experience which was encompassed by love and evolved from suffering to transformation within the context of the caregiving and post death period. However, for the participants to consciously ascribe meanings to the caregiving and describe them to us they needed to reflect on their overall caregiving experience. With regards to meaning Steeves and Kahn (1987) state that:

> When one is totally experiencing and completely involved in a lived experience, then one is involved in meaning and is part of that meaning. This total absorption in an experience elevates individuals above their own viewpoint and allows them to experience a larger picture (p. 115-116).

According to Frankl (1946/1984) people strive to find meaning in their personal existence to avoid the feeling of inner emptiness or void. Meaning is found by creating or doing something; by experiencing something (e.g. beauty in nature); or by "experiencing another human being in his very uniqueness – by loving him" (Frankl, 1946/1984, p. 134). Meaning is also found in the attitude we take towards unavoidable suffering; "when we are no longer able to change a situation . . . we are challenged to change ourselves" (Frankl, 1946/1984, p. 135). These three aspects that give meaning in life to individuals were present within and provided meanings in caregiving for the study participants.

Providing home-based care to their loved ones was in itself a source of meaning for the research participants. This was reflected in their total involvement in caregiving such that participants spoke of 'missing the doing of things' for their loved ones; therefore, life seemed 'empty' after the death of their loved ones. Meaning was also noted in the day to day management of caregiving by the study participants. The above discussion reflects the finding of meaning in the creating or doing of something (Frankl, 1946/1984).

The theme of love reflected the second aspect of finding meaning; that is, in loving another human being. This was reflected in the overall positive tone of the interviews and in the participants' statements of being 'happy to do it' (caregiving) in spite of all the difficulties encountered during this time. Love, which consisted of connection, closeness, caring, etc. was the primary reason the study participants chose to provide home-based care to their loved ones and it also was the factor that sustained them through this period which had its negative

aspect in the suffering experienced by them. Love was the overall emotion that encompassed suffering and transformation during caregiving and post death.

Suffering in itself may not provide meaning; that is, it may be difficult to see meaning in it while in the process of suffering; the meaning in suffering may be realised afterwards (Lindholm & Eriksson, 1993). Finding meaning in suffering is one way to go beyond it or transcend it and achieve healing (Cassell, 1982). Finding meaning in suffering requires self-reflection which leads to changes in personal thoughts and attitudes. Study participants were in different stages of this journey from suffering to transformation. Some had found meanings in caregiving and spoke of the growth and changes in themselves; they expressed that the caregiving experience was enriching. Others could not bring themselves to reflect on the experience as it caused suffering in the present.

According to Missinne (1984), suffering is unique and personal therefore the meaning found in suffering is also unique and subjective. Meaning is the outcome of the individual's reflection on their situation. The outcomes observed in this study varied for each participant; however, similarities were also present in that participants spoke of changes in self-perception, relationships, and attitude towards the world. Meaning in suffering was found by the study participants based on their reflections and attitude towards the unavoidable suffering. This issue of finding meaning in suffering has been discussed to some extent within the health literature (Cassell, 1982; Kahn & Steeves, 1995; Moulyn, 1982; Steeves & Kahn, 1987). These authors have identified transcendence as the usual outcome of finding meaning in suffering

My reflections on the data enabled me to see the whole integrated picture of informal caregiving. In the analysis I have tired to present the total picture in pieces. That is, I have discussed the caregiving context and time period as a critical time for the caregivers; I have elaborated on the three dimensions (love, suffering and transformation) of the caregiving experience; and I have discussed the meanings found within caregiving. However, these are not separate aspects of caregiving and do not exist in a linear relationship to each other; but are intertwined together in the total picture of informal caregiving. In the following discussion I will consider the relationship of my findings to the literature on informal caregivers and outline the contributions of this study to the existing research on informal caregivers.

Relationship to Caregiving Literature

The experiential literature revealed the stress experienced by informal caregivers during the informal caregiving process (Matson, 1988; Hull, 1990; Norum, 1995; Martens & Davies 1990; Rose, 1998, 1999) and how informal caregivers managed themselves during this time (Thorne, 1984; Matson, 1988; Hull, 1992; Norum, 1995; Rose, 1998, 1999; Martens & Davies 1990). These issues were noted within this study under the theme of suffering. The study participants expressed stress and uncertainty due to lack of knowledge about the disease process and their physical health deteriorated because caregiving to the loved ones was the priority for the participants. The participants also spoke of keeping busy, taking each day at a time, and the support of family and friends as a way of managing themselves during the caregiving. This study confirms most of

the issues identified in these previous studies and shows that health professionals need to continuously and consciously be aware of the impact of caregiving on the informal caregivers.

The positive aspects of caregiving or the importance of finding meanings in caregiving have not been thoroughly explored within the cancer caregiving literature. The present study richly demonstrated the positive aspects of informal caregiving in the theme of love. Participants spoke of different aspects of love as noted in the sub-themes. The reviewed studies had not delineated this aspect of caregiving which in the present study was the all encompassing experience of caregiving. This study therefore adds to our understanding of the caregiving experience in that it elaborates on the dimension of love within the caregiving experience. Meaning in caregiving was embedded in the theme of love. Meaning is found in "experiencing another human being in his very uniqueness – by loving him" (Frankl, 1946/1984, p. 134). Meaning also emerged within the suffering; as noted earlier this has been discussed to some extent within the health literature.

The present study revealed the coexistence of both the positive and negative dimensions of informal caregiving. The theme of love was the predominantly positive emotion experienced while the theme of suffering was the negative dimension of caregiving. Researchers have commented on the simultaneous existence of both the negative and positive dimensions within caregiving. They have further stated that positive emotions (affect) assisted informal caregivers to adapt to the distress experienced as well as manage their

stress during caregiving by finding the meanings in caregiving (Folkman, 1997, Folkman & Moskowitz, 2000).

Researchers have explored the issue of finding meaning in caregiving and its use by informal caregivers to manage their stress during caregiving; this has been discussed as meaning-based coping (Folkman, 1997; Folkman & Greer, 2000; Park & Folkman, 1997). According to Folkman and Greer (2000) unresolved distress motivated further coping processes within the individuals and brought into play meaning-based coping. The authors described meaning-based coping as that which "helps the person relinquish untenable goals and formulate new ones, make sense of what is happening, and appraise benefit where possible" (Folkman & Greer, 2000, p. 13). According to Folkman (1997) and Park and Folkman (1997) meaning is created by finding a redeeming value in a loss, by finding/forming closer bonds with others who have shared the experience with one, and/or finding that the experience had clarified ones goals/priorities. Folkman (1997) described four types of coping that were associated with positive psychological states and consisted of searching for and finding positive meaning. These were positive reappraisal, problem-focused coping, spiritual beliefs and practices, and infusing ordinary events with positive meaning. These coping processes involved the activation of beliefs, values, and goals that helped define the positive significance of the experience.

Researchers have increasingly acknowledged the presence of positive emotions and have explored the relationship between finding meaning and the positive aspects of caregiving that occur concurrently with the negative. The

present study revealed that both negative and positive dimensions of the caregiving experience existed within the caregiving context; however, the positive dimension (love) was the overall encompassing aspect of the experience. This dimension motivated the caregiving, provided meaning in it and the outcome of finding meaning was observed in the transformation theme. The present research suggests that meaning in caregiving is an essential component of the caregiving experience and that it is generated primarily from the positive dimension of the experience. However, the conscious search for meanings may largely occur during suffering, which in the present study was the concurrently existing negative aspect of the caregiving experience.

Literature has described informal caregiving as a journey; as a movement from the realization of the terminal state to closure of caregiving and focusing on ones personal self (Hull, 1989); as a transition of fading away involving acceptance of the terminal state to reorientation of self to life and personal growth (Davies, Reimer, & Martens, 1990); and as the development of awareness to dying which included acceptance of and preparing for the death of the loved one (Yates & Stetz, 1999). These journeys described the forward movement of the caregiver from one state to another with overlap between them. The focus of the studies was the caregivers' experience of the terminal cancer and death of their loved ones. The present research was also described as a journey; however, the focus of this study was the in depth caregiving experience. Therefore, this study discussed the overall feelings and perceptions of the participants during this time period and not only their experience of the terminal cancer and death of their

loved ones. In this study the forward movement occurred from the state of suffering to transformation but the movement as well as the caregiving and post-death period were all encompassed by love. This research reflects the above studies in that the caregiving experience is better understood and described as a process that caregivers go through rather that as separate elements of caregiving.

The results from this study were similar to those noted by Enyert and Burman (1999). In this study the terminal caregiving context was the environment within which meanings were found and was interpreted as a critical and transitional time for the participants. There was total involvement in caregiving and an altered sense of time and space. Enyert and Burman (1999) described the context in a similar manner; however, their context included within it the supportive networks, caregiving tasks, caregiver education/experience, caregivers' articulation of their grief/loss, their financial situation, and caregiver fatigue. The present study described the experience of love and meaning was found to be embedded in it. This was similar to the descriptions of Enyert and Burman (1999) that caregivers found meaning in doing what was important for their loved ones and by being with them. The theme of transformation in this study was interpreted as the outcome of the caregiving experience; it occurred due to the process of reflection on caregiving. Enyert and Burman, (1999) stated that the consequences of caregiving involved the articulation of a distinct life view that evolved from the caregiving experience and a reaching out to others.

The differences between the two studies were noted in their research question and approach, and in their interpretations. Enyert and Burman, (1999)

assessed informal caregivers' sense of well being and their ability to transcend and find meaning in caregiving. The present study interpreted the caregiving context, experience and meanings in it. This study confirms some findings of the study by Enyert and Burman (1999), but does not describe in detail the different aspects of the caregiving context. However, it discusses in depth the entire caregiving experience and the meanings in it.

A general assessment of the caregiving literature revealed that most studies had analysed meaning within the caregiving context with caregivers of persons with chronic illnesses; that is, most research was on informal caregiving to the elderly and those with dementia primarily due to Alzheimer's disease. According to Farran (1997) research with caregivers of persons' with dementia was primarily from the stress and adaptation perspective; she further stated that this did not fully capture the phenomenon of caregiving or address the issue of how some caregivers did well under such difficult circumstances. The author proposed that the phenomenon of informal caregiving could be investigated from the existential perspective. Existentialism is described as an intuitive philosophical paradigm that addresses the human capacity to transcend and find meaning in difficult life experiences; it is based on ones values, freedom of choice, responsibility, and consequences of actions (Farran, 1997; Frankl, 1946/1984, 1978; Yalom, 1980).

Research by Farran, Keane-Hagerty, Salloway, Kupferer, and Wilken (1991) with caregivers of patients with Alzheimer's disease revealed that caregivers responded to their caregiving experience by valuing the positive

aspects of caregiving, making personal choices about caregiving and life, and by searching for meaning in caregiving and life. Farran and Keane Hagerty (1991) developed an interactive model for finding meaning through caregiving. The model was based on assumptions from existentialism and had five aspects to it:

1. The critical antecedents were characteristics that had to be present before the caregiving started and included four assumptions drawn from the work of Frankl (1946/1984, 1978). 1) People's values provided the basis for meaning – values could be creative and expressed through work, experiential expressed through relationships, and/or based on ones attitudes and beliefs about life. 2) People created meaning by making choices – individuals made choices in life and found meaning in them therefore meaning was unique and individually determined. 3) People had the responsibility for right action and conduct – people had the responsibility of dealing with difficult life situations but had the choice of how to respond to these events. 4) Meaning could be found at the provincial (particular situations and/or events) and ultimate (deep life experiences associated with spiritual and/or philosophical beliefs) levels.
2. The stages of caregiving included three crisis points that caregivers experienced in becoming caregivers. 1) Becoming aware of the troubling symptoms. 2) Obtaining and acknowledging the diagnosis. 3) Assuming the caregiving responsibilities.
3. The responses to caregiving included the four ways that caregivers made sense out of their caregiving experience. 1) Valuing the positive aspects of

the relationships and caregiving. 2) Making personal choices about caregiving and life. 3) Searching for provisional meaning in the situation. 4) Searching for ultimate meaning.

4. The fourth aspect of the model was the three phases of suffering that the caregivers' encountered during the process of caregiving. 1) Acknowledging the powerlessness and loss in the situation. 2) Accepting the situation. 3) Gaining solidarity in a changed situation – assuming responsibility for making choices and finding meaning in caregiving.
5. The outcomes evolved out of these four components and included finding or not finding meaning in caregiving.

Farran and Keane-Hagerty (1991) suggested that finding meaning in caregiving focused on answering the question what could one make out of the situation rather than why one was in the situation. Finding meaning was considered to be a unique individual process that was difficult and required time and effort. Not finding meaning had detrimental effects on both the caregivers and their loved ones. The above research and model was based on caregivers of patients with Alzheimer's disease. As noted it had evolved from the existential philosophy especially, as interpreted in existential psychology (Frankl, 1946/1984, 1978; Yalom, 1980). Within the informal caregiving literature these results seemed to be closest to my interpretation of the informal caregiving experience and meaning as it evolved from the data. Therefore, the themes of the present study will be discussed in light of the literature/model reviewed above.

The theme of love was the all encompassing aspect of caregiving in this study. Love was the motivation and the reason that participants chose to provide care at home for their loved ones dying of cancer. Love was expressed in the caring activities and close relationships with the loved one as well as intimate family and friends. Love was also seen as the factor that influenced the positive response by participants to the caregiving experience and their satisfaction with it. In this study love was the major antecedent factor to caregiving and related to the four aspects of values, making choices, responsibility for right action and conduct, and meaning. Love was seen as the main characteristic of the third aspect of the model explained above; responses to caregiving which included making personal choices about life and caregiving, valuing the positive aspects of caregiving and relationships, and searching for provisional/ultimate meaning. This aspect was expressed by the study participants in their choice to be caregivers, their involvement in caregiving in spite of difficulties and in their treasuring and enjoyment of the time spent with their loved ones. Participants also expressed their satisfaction in being caregivers and spoke about their self discovery/growth.

The theme of suffering in the study was expressed primarily in the watching of the suffering and deterioration of their loved ones, in the uncertainty and frustrations of the day to day living during this time, and in the recall of the memories of this time period. This corresponded to the suffering aspect of the model; acknowledging powerlessness and loss and accepting the situation. There is similarity in what was noted in this study to that which was expressed in the model but not a direct relationship. For example in the present study participants

had to accept the death of their loved ones while caregivers of patients with Alzheimer's disease accepted the gradual losses in cognitive faculties. Another issue was the time frame of the disease processes; Alzheimer's disease is chronic while terminal cancer has a shorter time frame.

The stages of caregiving as expressed in the model were not expressed in the same manner in this study as the focus of the study was terminal cancer caregiving. However, the stages relate to the caregiving and post death period in this study. The caregiving period in this study was described as an intense, enclosed boundaried space. The fifth aspect of the model by Farran and Keane-Hagerty (1991) described the outcomes of caregiving as finding meaning in caregiving. In the present study this related to the theme of transformation which was still an ongoing process for some of the participants.

This study investigated the experience of informal caregivers providing home based care to their loved ones dying of terminal cancer from a holistic perspective. The context of the study was the terminal caregiving period considered by caregivers as an involved enclosed time period. The three experiential themes that evolved were love, suffering, and transformation. Meaning in caregiving was embedded in the theme of love (values, choice, responsibility); the search for meaning was prompted in the theme of suffering (interpretation of the situation); and transformation was the outcome of the caregiving experience itself (provisional meaning) as well as an outcome of the process of reflection on the overall experience of caregiving (ultimate meaning). The results were regarded as closely related to the caregiving literature that had

utilised the existential paradigm in their discussions as it explained the complete caregiving experience (positive/negative) as well as the meaning in caregiving.

Reflection

The hermeneutic spiral involves a constant movement from the data to the literature and personal reflections on the outcomes. Therefore, I will conclude the chapter with reflections that relate to the insights gained from the study. In my preunderstandings I had described what I expected to find in the study; that is, suffering and transformation for the caregivers based on their reflections on the caregiving experience. This as well as love, an unexpected theme was observed.

My personal query was what made some caregivers different from others such that it was a pleasure to be with them when they were with their loved ones who were actively dying. I found my answer to that in the study. The study participants expressed fulfilment in spite of the presence of suffering. I saw love as the primary factor that made the study participants unique. I also saw the importance of finding meaning in ones situation as it enabled one to transcend oneself or the situation. I feel I have accompanied each participant in their caregiving journey and appreciate them for my increased awareness of the dynamics of informal caregiving. Now, I see clearly the interactions between the positive and negative dimensions of the informal caregiving experience as well as the fact that the positive aspects especially if they are consciously reflected upon by the informal caregiver enable the caregiver to transcend the negative elements of the caregiving experience. This awareness will be reflected in my future interactions with informal caregivers.

Another aspect that was brought into my awareness was the importance of reflection. I experienced that personally because almost each step of the data analysis included with it a step of personal reflective thinking. I also saw it within the study participants in that those who had looked back to their situation seemed to have gone beyond it. My misgivings prior to data analysis were that as researchers we ask too much from our participants. I perceived research interviews as intrusive and was not convinced that I would want to gather my data in that manner. Therefore, I was thankful for the opportunity to do a secondary analysis as that meant I would not be putting the participants through this intrusive process. However, with the data analysis I realised that although research interviews are difficult for the participants; they have their advantages in that they enable the participants to reflect on their caregiving. The research interview process may have helped some participants to come to terms with their present situation and transcend it.

Lastly, I experienced the process of the hermeneutic circle and became consciously aware of the unlimited spirals that one could traverse within it. I realised that it is an unending process and that at some point conscious decisions have to be made to stop. For example, I had to make a conscious decision to stop from going further into the existential literature due to time and knowledge limitations. I found this somewhat limiting at the time as I wanted to continue on and on, yet I also realised the importance of knowing and deciding when to stop.

IMPLICATION AND CONCLUSION

This chapter consists of the summary of the study, the practice and research implications, the limitations, and the insights gained during the process. I will begin with the summary of the study and then discuss the nursing practice and research implications. The chapter will conclude with the limitations of the study and personal insights.

Summary

With the increased incidence of cancer and the changes in the health care system informal caregivers are gradually assuming more responsibility for providing home based care to their loved during terminal cancer. The experiential literature on terminal cancer caregiving has identified the stress experienced by informal caregivers as well as the strategies they have used to manage the caregiving. Authors have also expressed informal caregiving as a journey from the awareness of the disease to acceptance of the terminal state/death and life after the death of the loved one. The meaning within the caregiving experience has not been elaborated in the existing literature. This study described and interpreted the caregiving experience of informal caregivers providing terminal cancer care to their loved ones at home and explored the meanings in the caregiving experience. This secondary analysis was guided by the interpretive approach and data analysis followed the hermeneutic spiral/circle.

The results were described, interpreted, and discussed in terms of the caregiving context; the experiential themes of love, suffering, and transformation; and the meaning embedded in caregiving. The terminal caregiving period was

described as an enclosed space with outsiders coming in and out of this space. The subjective perception of time was altered; that is it seemed a long time period for the participants. Research participants were completely involved with their loved ones and their life revolved around their loved ones. It was considered to be critical period of time in the life of the participants and was the context within which the three experiential themes of love, suffering and transformation evolved.

Love was described by the participants as a phenomenon consisting of emotions of deep connection with their loved ones, closeness with them where participants felt a personal need to be with their loved ones, caring and commitment to their loved ones where participants wanted to do what was best for their loved ones, and open communication with and deep respect for their loved ones. These aspects were revealed to be the attributes of love as identified in the reviewed studies on love. Love has been expressed as deep affection one feels for those with whom ones life is deeply intertwined (Hatfield & Walster, 1978). Love was the all encompassing phenomenon that was overwhelmingly expressed by all study participants and seemed to be the key positive aspect of the experience; it was present before, during, and after the caregiving period and was all enduring.

Suffering was experienced during the terminal caregiving by research participants primarily due to being present and witness to the suffering of their loved ones. Being present and watching the deterioration, losses, and pain of their loved ones was a major source of suffering for the participants. This aspect was strongly present such that the memories of it continued to cause suffering into the

post death period. Another aspect of the suffering related to the organisation and management of the day to day care, interaction with the health care system, and continuation of the day to day aspects of living. Based on the data and the reviewed literature, suffering was described as a negative, natural, subjective, individual, and complex experience that the participants consciously experienced during the terminal cancer caregiving period.

Transformation was the third theme that was discerned as part of the experience of caregiving. Research participants spoke of the changes they had experienced as a result of living through the dying of their loved ones. They talked about the changes they experienced within themselves such as finding aspects of themselves that they were not aware of, changes in interpersonal relationships both with their loved ones as well as with family and friends, and an expansion of their universe in terms of thinking of issues that they had not considered before. This dimension could not be explored in depth due to its sparse, inconsistent, and subtle presence. Based on the literature and the data, transformation was described as intrapersonal growth or inward expansion of ones boundaries, interpersonal development or outward expansion of oneself, and awareness of ones spiritual dimensions. Transformation/transcendence in informal caregivers was described as an expansion of consciousness whereby the informal caregivers became aware of their old and new self-views and integrated these views into their self-definition.

The relationship between the caregiving context and the three experiential themes was visualised as a journey encompassed by love, which evolved from

suffering to transformation within the caregiving and post death period. It was visualised as a journey due to the forward movement noted in it. The process could start any time from the cancer diagnosis of the loved ones to sometime before their death and may end some time after death. The study participants were at various points within this movement. Meaning in caregiving was found to be embedded within this caregiving context and experience. However, for the informal caregivers to reveal the meanings in caregiving they had to go through the process of reflection. Reflection was described as a critical process that occurred primarily during the phase of suffering for the participants; it was encompassed by love and the outcome of this critical reflective process was the transformation seen in the caregiver.

Meaning in caregiving was discussed based on the works of Frankl (1946/1984, 1978); and Farran (1997) who proposed that the phenomenon of informal caregiving be investigated from the existential perspective as it explained fully the caregiving experience (positive/negative) as well as the meaning in caregiving. Existentialism was described as an intuitive philosophical paradigm that addressed the human capacity to transcend and find meaning in difficult life experiences; it was based on ones values, freedom of choice, responsibility, and consequences of actions (Farran, 1997; Frankl, 1946/1984, 1978; Yalom, 1980). In this study meaning in caregiving was embedded in the theme of love (values, choice, responsibility); the search for meaning was prompted in the theme of suffering (interpretation of the situation); and transformation was the outcome of the caregiving experience itself (provisional

meaning) as well as reflection on the total caregiving experience (ultimate meaning).

This study has interpreted the caregiving experience from a broad holistic perspective; however, the caregiving experience and meaning within it as presented here do not seem to be new knowledge or understanding. As a formal caregiver I considered myself to be conversant with the informal caregivers' choice to provide home-based care to their loved ones during terminal cancer. That they do it out of feelings of love and that they suffer were part of my intuitive understanding of the experience. I had also noticed that this critical experience had a fundamental impact on the informal caregivers. If this is not new knowledge or understanding then in what way does this study contribute to our understanding of the informal caregiving experience? This study described and discussed in depth the different coexisting components of the informal caregiving experience, their interrelationships, and the meaning in caregiving. By doing so, the entire caregiving experience is brought into awareness afresh. Thus, this study contributes to the existing knowledge of the informal caregiving experience by enhancing our understanding of the overall experience and the meaning in it. By being more fully aware of the informal caregiving process and the meaning in it, formal caregivers can participate deeply in the caregiving process and be there (present) for the informal caregivers.

Practice Implication

The caregiving literature reviewed in the last chapter indicated the importance of finding meaning within the caregiving context. Meaning in caregiving has been explored from both the existential (Frankl, 1946/1984, 1978; Farran, 1997; Farran et al, 1991; Farran & Keane-Hagerty, 1991) and the stress and coping perspective (Folkman, 1997; Folkman & Greer, 2000; Park & Folkman, 1997). According to Kellett (1997) informal caregivers' ability to view their experience and attribute meaning to it enabled them to ascribe meaning to their existence as caregivers. Farran et al. (1991) have observed that informal caregivers responded to their caregiving experience by valuing the positive aspects of caregiving, making personal choices about caregiving and life, and by searching for meaning in caregiving and life.

These observations reveal that finding meaning within the caregiving situation is an integral component of the caregiving experience. Health professionals need to consciously be aware of this aspect of the caregiving experience in order to assist informal caregivers in their search to find meaning in their experience. Health professionals could assist the informal caregivers by acknowledging the unique individuality of each caregiver; by doing so we show our respect for them and their caregiving. In this manner we allow them to explore their situation openly, in a non judgmental atmosphere and construct their own meaning from it. We need to actively listen to their stories and promote the sense that we have the time to listen; in the telling of their stories caregivers go

through the process of reflection and internalise their experience as well as the learning from it.

We need to acknowledge that the terminal cancer caregiving period is a critical time for caregivers and that they may be questioning all aspects of their lives and spirituality during this time. Our presence and acknowledgment of this provides them with the opportunity to express themselves within a safe environment. The notion of presence has been recognised in the nursing profession and authors have suggested that nurses can be present to the patient and their families in a deep caring manner (Parse, 1981). Putting into practice the interventions described above of acceptance, active listening, presence and strategies that help them to reflect on their experience would enable the health professionals to enter into a deeper relationship with the informal caregivers.

Reflection assists one to create and clarify the meaning of an experience in terms of the self; that is, an experience is examined to create meaning that focuses on concerns that are central to the individual. The outcome of the reflective process is usually a change in ones perspective (Boyd & Fales, 1983). In this study it was observed that reflection was required for the forward movement from suffering to transformation/transcendence to take place for the participants. In the nursing literature reflection has been discussed as a learning strategy and is considered critical for experiential learning to occur (Atkins & Murphy 1993; Lauterbach & Becker, 1996). Reflection does not seem to have received specific attention within the caregiving literature. The observance of this dimension within

the caregiving experience suggests that health professionals need to promote reflection in informal caregivers in order to assist them in their journey of life.

The critical reflective process could be promoted by encouraging the informal caregivers to describe their caregiving experience as in the description the whole is seen again and one learns from it. Active listening would enable the health professionals to facilitate the process of critical analysis of the experience by the informal caregiver because they would be sensitive to what the caregivers are saying as well as not saying and could guide them with appropriate questions. By encouraging and allowing informal caregivers to mirror back to us their experience and understanding of it we would promote their own integration and evaluation of the experience. Another method that could be promoted is the use of a self-reflective journal by the informal caregivers. Reading a particular event in the journal a few days/weeks after the event was recorded may stimulate a different interpretation of the event.

Health professionals as formal caregivers may be aware of the element of love within the informal caregiving environment. However, my sense is that we do not pay close attention to it, or think about how it promotes a sense of the positive within the caregiving environment. It took the in depth analysis of this study for me to realise that love enabled the informal caregivers in the study to find fulfillment in their caregiving in spite of the suffering. Health professionals need to be consciously aware of this and consider both the positive and negative elements of the caregiving situation rather than focus on the negative aspects due to the abundant documentation on the negative impact of caregiving. This does

not mean that informal caregiving is not difficult; but the awareness of the total caregiving experience may make us change our approach to the informal caregivers. This study provides us with deeper insight into the total phenomenon of informal caregiving. The fact that it is a unique process for each caregiver and that within the informal caregiving journey each caregiver is situated at a different point. Therefore, we need to approach each caregiver as a unique person operating from their own reality and framework.

This study highlighted the existential issues faced by informal caregivers; issues of life, meaning, death, and spirituality. Health professionals need to be aware of the existential issues that patients as well as caregivers may face during the terminal caregiving period, especially if they are working with palliative care patients and their caregivers. This is a specific area of knowledge and health professionals may not have explored it fully within their basic education program. Therefore, in-service courses within hospitals on issues such as these and how health professionals could assist informal caregivers and their loved ones in facing the existential issues would be extremely useful.

As formal caregivers, each one of us needs to critically analyse their relationship with the informal caregivers especially in the current environment of increased home based informal caregiving. Ward-Griffin and McKeever (2000) reported that the relationship between the formal and informal caregivers did not reflect a true partnership where both caregivers contributed to patient care but was of an exploitative nature. The present research revealed that informal caregivers' interactions with formal caregivers were both positive and negative. This means

that we do not have consistent relationships with informal caregivers as true partners in care. A personal critical analysis of our relationship with informal caregivers may enable us to be consistent in our approach to informal caregivers and work with them as true partners.

Research Implication

A number of areas discovered in the study could be explored more thoroughly with informal caregivers of cancer patients. My sense is that we tend to take love for granted; therefore, within the health care literature love has received minimal attention though love as a concept has been researched and explained well in psychology (Sternberg & Barnes, 1988). This study revealed love as an essential element of informal caregiving; we need to explore the positive contribution of love to informal caregiving, the relationship between love and informal caregiving, and the health professionals' awareness of love as an aspect of informal caregiving. Meaning was observed to be an essential component of the informal caregiving experience. Though the experiential studies of informal caregivers of cancer patients have described the caregiving experience, meaning in the experience has not been investigated thoroughly. We still lack studies that investigate fully the phenomenon of meaning in informal caregiving to persons with advanced cancer.

Transformation/transcendence is considered to be the outcome of finding meaning within an experience; however, this does not occur instantly or without effort but requires reflection on the experience. Nursing literature has investigated reflection as a process that could be used to facilitate experiential learning in

nursing; keeping a personal journal being a key way to reflect on ones learning (Lauterbach & Becker, 1996). We need to investigate how the process of reflection enables the informal caregivers to move from suffering to transcendence. Another aspect would be studies that examine whether formal caregivers facilitate the reflective process in informal caregivers and if they do how this benefits the informal caregiver.

The present study interpreted the results from an existential perspective based on the works of Frankl (1946/1984, 1978) and Farran (1997). However, a framework that explains informal terminal cancer caregiving from the existential perspective was not developed in this study. This could be a promising area for future research. Although this study was not approached from a nursing theory perspective; Parse's theory of human becoming based on existentialism could be explored and used to guide future research on informal caregiving as it seems applicable and has been used to explore the phenomenon of suffering in patients and caregivers (Young, Taylor, & McLaughlin-Renpenning, 2001). Also, this study was not approached from the stress and adaptation perspective which has identified meaning-based coping within the stress and coping framework (Folkman, 1997; Folkman & Greer, 2000). Future studies could explore this dimension with informal caregivers of persons with advanced cancer.

The data for this study were collected in the post death period; caregiving in the study was primarily described as a positive experience. The experiential studies included in the literature review were primarily done during the actual caregiving period. The caregivers in those studies had expressed the caregiving

period as stressful with caregivers using various strategies to manage themselves. Is this difference in expression; that is, negative during caregiving and positive after caregiving, due to the timing of the data collection? Is the positive bias in the data due to a selection bias; that is caregivers who had a positive experience were the ones who volunteered for the study? A longitudinal study with data collection during the caregiving and post death period may resolve some of these issues. A longitudinal study would also portray the long term outcomes of caregiving as well as illustrate the caregiving process and the movement that occurs within it as the caregivers move from the caregiving to the post death period and thereafter.

Limitation

A limitation of this study was related to the nature of secondary data analysis. The analysis was done after the completion of the primary study. As the themes developed I was not able to go back to the participants and explore them in depth or obtain clarification from the participants. I especially noted this with the transformation theme; this was not explored or uniformly addressed in the primary study and therefore is not well developed in this study.

My engagement with the data revealed that most participants appreciated the opportunity to express their thoughts and feelings about their caregiving experience; although it was distressing during the interview itself they felt that they benefited by going through their experience again in describing it. My sense of limitation comes from the fact that, had I been part of the primary research I could have in the process of conducting the research interviews been of some assistance to the participants. This study shows that post death interviews with

informal caregivers do not cause undue distress and is similar to the findings of Seamark, Gilbert, Lawrence, and Williams (2000).

In qualitative research the data is interpreted from the perspective of the researcher. Although I have given a summary of my preunderstandings in the last chapter to bring forth and acknowledge my personal biases; I acknowledge that it is almost impossible for me to consciously recognise all the personal biases that may have been operating within me during the data analysis. I acknowledge that the present study may contain personal biases in spite of the continual reflections during the data analysis. Some of these biases may be due to my personal values and beliefs as well as my personal philosophy and worldview. These may have affected how the study unfolded within me and in these pages.

Conclusion

The research process and the writing of this thesis was a solitary journey into the realms of knowledge. My primary gain during this endeavour was an expansion of my knowledge base both in depth and breadth. For example I developed a comprehensive understanding of love and learnt about existentialism; an area that I knew very little about. This research also made me re-examine my relationship with informal caregivers; it has enabled me to see the informal caregivers with new eyes and perceive the beauty in them.

Love is the essence of meaning

الله

REFERENCE

Abel, E., & Sherman, J. J. (1991). Use of national data sets to teach graduate students research skills. *Western Journal of Nursing Research, 13*(6), 794-797.

Acton, G. J. (2002). Self-transcendent views and behaviors: Exploring growth in caregivers of adults with dementia. *Journal of Gerontological Nursing, 28*(12), 22-30.

Acton, G. J., & Wright, K. B. (2000). Self-transcendence and family caregivers of adults with dementia. *Journal of Holistic Nursing. 18*(2), 143-158.

Allen, M. N., & Jensen, L. (1990). Hermeneutical inquiry: Meaning and scope. *Western Journal of Nursing Research, 12*(2), 241-253.

Atkins, S., & Murphy, K. (1993). Reflection: A review of the literature. *Journal of Advanced Nursing, 18*, 1188-1192.

Ayres, L. (2000). Narratives of family caregiving: The process of making meaning. *Research in Nursing and Health, 23,* 424-434.

Barer, B. M., & Johnson, C. L. (1990). A critique of the caregiving literature. *The Gerontologist, 30*(1), 26-29.

Baum, S. K., & Stewart, R. B. (1990). Sources of meaning through the lifespan, *Psychological Reports, 67*(1), 3-14.

Beck, C. T. (1993). Qualitative research: The evaluation of its credibility, fittingness, and auditability. *Western Journal of Nursing Research, 15*(2), 263-266.

Bowers, B. J. (1987). Intergenerational caregiving: Adult caregivers and their ageing parents. *Advances in Nursing Science, 9*(2), 20-31.

Boyd, E. M., & Fales, A. W. (1983). Reflective learning: Key to learning from experience. *Journal of Humanistic Psychology, 23*(2), 99-117.

Bridges, W. (2001). The way of transition: Embracing life's most difficult moments. Cambridge, MA: Perseus.

Bull, M. (1990). Factors influencing family caregiver burden and health. *Western Journal of Nursing Research, 12*(6), 758-776.

Burstein, L. (1978). Secondary analysis: An important resource for educational research and evaluation. *Educational Researcher, 7*(5), 9-12.

Calman, K. C., & Welsh, J. (1984). Physical aspects. In D. C. Saunders (Ed.), *The management of terminal malignant disease* (2nd ed. pp. 31-42). London: Edward Arnold.

Canadian Institute for Health Information. (2000). *Health care in Canada: A first annual report.* Ottawa, Canada: Author.

Cassell, E.J. (1982). The nature of suffering and the goals of medicine. *New England Journal of Medicine, 306,* 639-645.

Cassell, E. J. (1991). Recognizing suffering. *Hastings Center Report, 21*(3), 24-31.

Cherny, N. I., Coyle, N., & Foley, K. M. (1994). Suffering in the advanced cancer patient: A definition and taxonomy. *Journal of Palliative Care, 10*(2), 57-70.

Copp, L. A. (1990). The spectrum of suffering. *American Journal of Nursing, 90,* 35-39. (Original work published 1974).

Coward, D. D. (1990). The lived experience of self-transcendence in women with advanced breast cancer. *Nursing Science Quarterly, 3*, 162-169.

Davis, L. L. (1992). Building a science of caring for caregivers. *Family community Health, 15*(2), 1-9.

Davies, B., Reimer, J. C., & Martens, N. (1990). Families in supportive care. Part I: The transition of fading away: The nature of the transition. *Journal of Palliative Care, 6*(3), 12-20.

Desjarlais, R. (1994). Struggling along: The possibilities for experience among the homeless mentally ill. *American Anthropologist, 96*(4), 886-901.

Ellis, J. (1998). Interpretive inquiry as a formal research process. In J. Ellis (Ed.), *Teaching from understanding: Teacher as interpretive inquirer* (pp. 15-32). New York: Garland.

Enyert, G., & Burman, M. E. (1999). A qualitative study of self-transcendence in caregivers of terminally ill patients. *American Journal of Hospice & Palliative Care, 16*(2), 455-62.

Eriksson, K. (1992). The alleviation of suffering: The idea of caring. *Scandinavian Journal of Caring Sciences, 6*(2), 119-123.

Estabrooks, C. A., & Romyn, D. M. (1995). Data sharing in nursing research: Advantages and challenges. *Canadian Journal of Nursing Research, 27*(1), 77-88.

Fabry, J. (1996). Use of the transpersonal in Logotherapy. In S. Boorstein (Ed.), *Transpersonal psychotherapy* (2nd ed., pp. 101-115). Albany: State University of New York Press.

Farran, C. J. (1997). Theoretical perspectives concerning positive aspects of caring for elderly persons with dementia: Stress/adaptation and existentialism. *The Gerontologist, 37*(2), 250-256.

Farran, C. J., & Keane-Hagerty, E. (1991). An interactive model for finding meaning through caregiving. In P. L. Chinn (Ed.), *Anthology on caring* (pp. 225-237). New York: National League for Nursing.

Farran, C. J., Keane-Hagerty, E., Salloway, S., Kupferer, S., & Wilken, C. S. (1991). Finding meaning: An alternative paradigm for Alzheimer's disease family caregivers. *The Gerontologist, 31*(4), 483-489.

Fehr, B. (1988). Prototype analysis of the concepts of love and commitment. *Journal of Personality and Social Psychology, 55*(4), 557-579.

Fehr, B. (1994). Prototype-based assessment of laypeople's views of love. *Personal Relationships, 1*, 309-331.

Fehr, B., & Russell, J. A. (1991). The concept of love viewed from a prototype perspective. *Journal of Personality and Social Psychology, 60*(3), 425-438.

Ferguson, M. (1980). *The Aquarian conspiracy: Personal and social transformation in the 1980s*. Los Angeles: J. P. Tarcher.

Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social Science and Medicine, 45*(8), 1207-1221.

Folkman, S., & Greer, S. (2000). Promoting psychological well-being in the face of serious illness: When theory, research, and practice inform each other. *Psycho-Oncology, 9*, 11-19.

Folkman, S., & Moskowitz, J. T. (2000). Positive affect and the other side of coping. *American Psychologist, 55*(6), 647-654.

Frankl, V. E. (1966). Self-transcendence as a human phenomenon. *Journal of Humanistic Psychology, 6*(2), 97-106.

Frankl, V. E. (1978). *The unheard cry for meaning: Psychotherapy and humanism*. New York: Simon and Schuster.

Frankl, V. E. (1984). *Man's search for meaning.* New York: Pocket Books. (Original work published 1946).

Fromm, E. (1956). *The art of loving.* (R. N. Anshem, Ed.). New York: Harper.

Gadamer, H-G. (1975). *Truth and method.* London: Sheed and Ward.

Geanellos, R. (1998a). Hermeneutic Philosophy. Part I: Implication of its use as methodology in interpretive nursing research. *Nursing Inquiry, 5*, 154-163.

Geanellos, R. (1998b). Hermeneutic Philosophy. Part II: A nursing research example of the hermeneutic imperative to address forestructures/preunderstandings. *Nursing Inquiry, 5*, 238-247.

Geanellos, R. (2000). Exploring Ricoeur's hermeneutic theory of interpretation as a method of analyzing research texts. *Nursing Inquiry, 7*, 112-119.

George, L. K. (1993). Sociological perspectives on life transitions. *Annual Review of Sociology, 19*, 353-373.

Given, B., Strommel, M., Collins, C., King, S., & Given, C. W. (1990). Responses of elderly spouse caregivers. *Research in Nursing and Health, 13,* 77-85.

Gregory, D., & English, J. C. B. (1994). The myth of control: Suffering in palliative care. *Journal of Palliative Care, 10*(2), 18-22.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). Thousand Oaks, CA: Sage.

Guba, E. G., & Lincoln, Y. S. (1981). *Effective evaluation*. San Francisco: Jossey-Bass.

Hanna, F. J., Giordano, F., Dupuy, P., & Puhaka, K. (1995). Agency and transcendence: The experience of therapeutic change. *Humanistic Psychologist, 23*(2), 139-160.

Hatfield, E., & Walster, G. W. (1978). A new look at love. Reading, MA: Addison-Wesley.

Hazo, R. G. (1967). The idea of love. New York: F A Praeger.

Hedrick, T. E. (1988). Justification for the sharing of social science data. *Law and Human Behavior, 12*(2), 163-171.

Herron, D. G. (1989). Secondary data analysis: Research method for the clinical nurse specialist. *Clinical Nurse Specialist, 3*(2), 66-69.

Hinds, P. S., Vogel, R. J., & Clarke-Steffen, L. (1997). The possibilities and pitfalls of doing a secondary analysis of a qualitative data set. *Qualitative Health Research, 7*(3), 408-424.

Huberman, A. M., & Miles, M. B. (1998). Data management and analysis methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Collecting and interpreting qualitative materials* (pp. 179-210). Thousand Oaks, CA: Sage

Hull, M. M. (1989). Family needs and supportive nursing behaviours during terminal cancer: A review. *Oncology Nursing Forum, 16*(6), 787-792.

Hull, M. M. (1990). Sources of stress for hospice caregiving families. *Hospice Journal, 6*(2), 29-54.

Hull, M. M. (1992). Coping strategies of family caregivers in hospice homecare. *Oncology Nursing Forum, 19*(8), 1179-87.

Jacobson, A. F., Hamlton, P., & Galloway, J. (1993). Obtaining and evaluating data sets for secondary analysis in nursing research. *Western Journal of Nursing Research, 15*(4), 483-494.

Jaffe, D. T. (1985). Self-renewal: Personal transformation following extreme trauma. *Journal of Humanistic Psychology, 25*(4), 99-124.

Johnson-Laird, P. N., & Oatley, K. (1989). The language of emotions: An analysis of a semantic field. *Cognition and Emotion, 3*(2), 81-123.

Kahn, D. L. & Steeves, R. H. (1986). The experience of suffering: Conceptual clarification and theoretical definition. *Journal of advanced Nursing, 11*, 623-631.

Kahn, D. L. & Steeves, R. H. (1995). The significance of suffering in cancer care. *Seminars in Oncology Nursing, 11*(1), 9-16.

Kellett, U. M. (1997). Heideggerian phenomenology: An approach to understanding family caring for an older relative. *Nursing Inquiry, 4*(1), 57-65.

Koop, P. M., & Strang, V. R. (2003). The bereavement experience following home-based family caregiving for persons with advanced cancer. *Clinical Nursing Research, 12*(2), 127-144.

Kovecses, Z. (1986). *Metaphors of anger, pride, and love: A lexical approach to the structure of concepts*. Philadelphia: J. Benjamins.

Kovecses, Z. (1991). A linguist's quest for love. *Journal of Social and Personal Relationships, 8,* 77-97.

Lauterbach, S. S., & Becker, P. H. (1996). Caring for self: Becoming a self-reflective nurse. *Holistic Nursing Practice, 10*(2), 57-68.

Lee, J. A. (1977). A typology of styles of loving. Personality and Social Psychology Bulletin, 3, 173-182.

Lev, E. L., & McCorkle, R. (1998). Loss, grief, and bereavement in family members of cancer patients. *Seminars in Oncology Nursing, 14*(2), 145-151.

Levy, D. (1979). The definition of love in Plato's symposium. *Journal of the History of Ideas, 40*(2), 285-291.

Lewis, C. S. (1960). *The four loves*. New York: Harcourt Brace Jovanovich.

Lindholm, L., & Eriksson, K. (1993). To understand and alleviate suffering in a caring culture. *Journal of Advanced Nursing, 18*, 1354-1361.

Martens, N., & Davies, B. (1990). The work of patients and spouses in managing advanced cancer at home. *Hospice Journal, 6*(2), 55-73.

Martin, L. A. (1986). *The experience of time*. Unpublished master's thesis, University of Alberta, Edmonton, Canada.

Maslow, A. H. (1969). Various meanings of transcendence. *Journal of Transpersonal Psychology, 1*(1), 56-66.

Matson, C. A. (1988). Families with a terminally ill member: A grounded theory of family relationships. *American Journal of Hospice Care, 5,* 38-41.

McArt, E. W., & McDougal, L. W. (1985). Secondary data analysis: A new approach to nursing research. *Image: Journal of Nursing Scholarship, 17*(2), 54-57.

McCusker, J. (1984). The terminal period of cancer: Definition and descriptive epidemiology. *Journal of Chronic Diseases, 37*(5), 377-385.

Missinne, L. E. (1984, March). Reflections on the meaning of suffering. *The Priest,* 11-13.

Morse, J. M. (1994). Emerging from the data: The cognitive processes of analysis in qualitative inquiry. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp.23-43). Thousand Oaks, CA: Sage.

Moulyn, A. C. (1982). *The meaning of suffering: An interpretation of human existence from the viewpoint of time*. Westport, CT: Greenwood Press.

National Cancer Institute of Canada. (1997, August 28). National cancer control strategy needed to meet challenge of rising cancer incidence. *National*

Cancer Institute of Canada Media Release [on-line]. Available: http://www.ncic.cancer.ca/pubs/media/97/aug28e.htm

National Cancer Institute of Canada. (2000). *Canadian cancer statistics.* Toronto, Canada: Author.

National Cancer Institute of Canada. (2003). *Canadian cancer statistics.* Toronto, Canada: Author.

Northouse, L. (1984). The impact of cancer of the family: An overview. *International Journal of Psychiatry Medicine, 14,* 215-242.

Norum, J. (1995). Cancer patients dying at home: Care providers' experience. *Journal of Cancer Care, 4,* 157-160.

Park, C. L., & Folkman, S. (1997). Meaning in the context of stress and coping. *Review of General Psychology, 1*(2), 115-144.

Parse, R. R. (1981). *Man-living-health: A theory of nursing.* New York: Wiley.

Pepin, J. I. (1992). Family caring and caring in nursing. *Image: Journal of Nursing Scholarship, 24*(2), 127-131.

Petrick, T. R. (1991). *Personal health and the demands of caregiving.* Unpublished master's thesis, University of Alberta, Edmonton, Canada.

Polk, G. C. (1986). Subjective time orientation. *Nursing Success Today, 3*(7), 11-18.

Poirier, S., & Ayres, L. (1997). Endings, secrets, and silences: Overreading in narrative inquiry. *Research in Nursing and Health, 20,* 551-557.

Reed, P. G. (1991). Self-transcendence and mental health in oldest-old adults. *Nursing Research, 40*(1), 5-11.

Reed, P. G. (1996). Transcendence: Formulating nursing perspectives. *Nursing Science Quarterly, 9*(1), 2-4.

Richardson, L. (1998). Writing: A method of inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), *Collecting and interpreting qualitative materials* (pp. 345-371). Thousand Oaks, CA: Sage.

Richer, M., & Ezer, H. (2000). Understanding beliefs and meanings in the experience of cancer: A concept analysis. *Journal of Advanced Nursing, 32*(5), 1108-1115.

Ricoeur, P. (1974). The conflict of interpretations: Essays in hermeneutics. (D. Ihde Ed., K. McLaughlin Trans.). Evanston, IL: Northwestern University Press.

Ricoeur, P. (1981) *Hermeneutics and the human sciences: Essays on language, action and interpretation* (J. B. Thompson, Trans. and Ed.). London: Cambridge University. (Original works published 1970-1979).

Rodgers, B. L., & Cowles, K. V. (1993). The qualitative research audit trail: A complex collection of documentation. *Research in Nursing and Health, 16*, 219-226.

Rodgers, B. L., & Cowles, K. V. (1997). A conceptual foundation for human suffering in nursing care and research. *Journal of Advanced Nursing, 25*(5), 1048-1053.

Rose, K. E. (1998). Perceptions related to time in a qualitative study of informal carers of terminally ill cancer patients. *Journal of Clinical Nursing, 7*(4), 343-350.

Rose, K. E. (1999). A qualitative analysis of the informational needs of informal carers of terminally ill cancer patients. *Journal of Clinical Nursing, 8*(1), 81-88.

Rubin, Z. (1970). Measurement of romantic love. *Journal of Personality and Social Psychology, 16*, 265-273.

Rubin, Z. (1973). *Liking and Loving: An invitation to social psychology*. New York: Holt, Rinehart, and Winston.

Russell, J. A. (1991). In defense of a prototype approach to emotion concepts. *Journal of Personality and Social Psychology, 60*(1), 37-47.

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Sciences, 8*(3), 27-37.

Sanders, S. A. (1986). Development of a tool to measure subjective time experience. *Nursing Research, 35*(3), 178-182.

Schwandt, T. A. (1994). Constructivist, interpretivist approaches to human inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 118-137). Thousand Oaks, CA: Sage.

Seamark, D. A., Gilbert, J., Lawrence, C. J., & Williams, S. (2000). Are postbereavement research interviews distressing to carers? Lessons learned from palliative care research. *Palliative medicine, 14*, 55-56.

Seltzer, M. M., & Li, L. W. (1996). The transitions of caregiving: Subjective and objective definitions. *The Gerontologist, 36*(5), 614-626.

Seltzer, M. M., & Li, L. W. (2000). The dynamics of caregiving: Transitions during a three-year prospective study. *The Gerontologist, 40*(2), 165-178.

Shaver, P. R., & Hazan, C. (1988). A biased overview of the study of love. *Journal of Social and Personal relationships, 5*, 473-501.

Shaver, P. R., Morgan, H. J., & Wu, S. (1996). Is love a 'basic' emotion? *Personal Relationships, 3*, 81-96.

Shaver, P., Schwartz, J., Kirson, D., & O'Connor, C. (1987). Emotion knowledge: Further exploration of a prototype approach. *Journal of Personality and Social Psychology, 52*(6), 1061-1086.

Smith, D. G. (1991). Hermeneutic inquiry: The hermeneutic imagination and the pedagogic text. In E. C. Short (Ed.), *Forms of curriculum inquiry* (pp. 187-209). Albany, NY: SUNY Press.

Smith, J. K. (1992). Interpretive inquiry: A practical and moral activity. *Theory into Practice, 31*(2), 100-106.

Steeves, R. H. & Kahn, D. L. (1987). Experience of meaning in suffering. *Image: Journal of Nursing Scholarship, 19,* 114-116.

Sternberg, R. J. (1986). A triangular theory of love. *Psychological Review, 93*(2), 119-135.

Sternberg, R. J., & Barnes, M. L. (Eds.). (1988). *The psychology of love*. New Haven: Yale University Press.

Sternberg, R. J., & Grajek, S. (1984). The nature of love. *Journal of Personality and Social Psychology, 47*(2), 312-329.

Strang, V. R., & Koop, P. M. (2003). Factors which influence coping: Home-based family caregiving of persons with advanced cancer. Journal of Palliative Care, 19(2), 107-114.

Strang, V. R., Koop, P. M., & Peden, J. (1999). *The experience of respite during home-base family caregiving for persons with advanced cancer.* Edmonton, Canada: University of Alberta, Faculty of Nursing.

Strang, V. R., Koop, P. M., & Peden, J. (2002). The experience of respite during home-base family caregiving for persons with advanced cancer. *Journal of Palliative Care, 18*(2), 97-104.

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research* (2nd ed.). Thousand Oaks, CA: Sage.

Strumpf, N. E. (1987). Probing the temporal world of the elderly. *International Journal of Nursing Studies, 24*(3), 201-214.

Swanson, E. A., Jensen, D. P., Specht, J., Johnson, M. L., & Maas, M. (1997). Caregiving: Concept analysis and outcomes. *Scholarly Inquiry for Nursing Practice: 11*(1), 65-76.

Swensen, C. H. (1972). The behaviour of love. In H. A. Otto (Ed.), *Love today: A new exploration* (pp. 86-101). New York: Association Press.

Szabo, V., & Strang, V. R. (1997). Secondary analysis of qualitative data. *Advances in Nursing Science, 20*(2), 66-74.

Thorne, S. (1984). The family cancer experience. *Cancer Nursing, 8,* 285-291.

Thorne, S. (1994). Secondary analysis: Issues and implications. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp.263-279). Thousand Oaks, CA: Sage.

Travelbee, J. (1971). *Interpersonal aspects of nursing*. Philadelphia: F. A. Davies.

Vigano, A., Bruera, E., & Suarez-Almazor, M. E. (1999). Terminal cancer syndrome: Myth or reality? *Journal of Palliative Care, 15*(4), 32-39.

Wade, G. H. (1998). A concept analysis of personal transformation. *Journal of Advanced Nursing, 28*(4), 713-719.

Ward-Griffin, C., & McKeever, P. (2000). Relationships between nurses and family caregivers: Partners in care? *Advances in Nursing Science, 22*(3), 89-103.

Watson, S. J. (1991). An analysis of the concept of experience. *Journal of Advanced Nursing, 16,* 1117-1121.

Webster's encyclopedic unabridged dictionary of the English language. (1989). New York: Gramery Books.

Wilson, *W.*, Balszer, D. G., & Nashold, B. S. (1976). Observations on pain and suffering. *Psychosomatics, 17*(2), 73-76.

World Health Organization. (1990). *Cancer pain relief and palliative care.* Geneva, Switzerland: Author.

World Health Organisation. (2003). *Global action against cancer.* Geneva, Switzerland: Author.

Yalom, I. D. (1980). *Existential Psychotherapy*. New York: Basic Books.

Yalom, I. D. (1982). The 'terrestrial' meanings of life. *International Forum for Logotherapy, 5*(2), 92-102.

Yates, P., & Stetz, K. M. (1999). Families' awareness and response to dying. *Oncology Nursing Forum, 26*(1), 113-120.

Young, A., Taylor, S. G., & McLaughlin-Renpenning, K. (2001). *Connections: Nursing research, theory, and practice*. St. Louis, MO: Mosby.

APPENDIX A

Primary Study: Ethics Approval

University of Alberta
Edmonton

Canada T6G 2G3

Faculty of Nursing

3rd Floor Clinical Sciences Building

Certification of Ethical Acceptability for Research Involving Human Subjects

---

NAME OF APPLICANT(S): Dr. Vicki Strang, et al.

TITLE OF PROJECT: "The Experience of Respite During Home-Based Family Caregiving for Persons with Advanced Cancer"

The members of the review committee, having examined the application for the above named project, consider the procedures, as outlined by the applicants, to be acceptable on ethical grounds for research involving human subjects.

11 Jan. 97
Date

Beverley O'Brien, DNS
Chair, Ethics Review Committee

ERC 97-132
5005-02-132

Capital Health

Regional Research Administration Office
CSB 9-122, 492-1372

Memorandum

NOTICE OF APPROVAL FOR PROPOSED RESEARCH
HOME CARE

Project Title:	The Experience of Respite During Home-Based Family Caregiving for Persons with Advanced Cancer
Project No.:	S-90
Investigator(s):	Dr. V. Strang
Department:	Faculty of Nursing
Division:	-
Address:	CSB 3rd Floor
Phone/FAX:	

Supporting documents:

1)	Ethical Approval	July 1997
2)	Study Protocol	Received
3)	Funds:a) Source b) Type	Edna Minton Foundation Grant
4)	Overhead Negotiated	N/A
5)	Account #	Account will be held at the Faculty of Nursing **Please advise the Regional Research Administration Office CSB 9-122 when you have received funding.**
6)	Contract	N/A

Project Approved September 1997

THIS APPROVAL IS **VALID FOR ONE YEAR**

By _____

Title Maureen Bain, Manager
Regional Research Administration

Copies to: Department Chair,Health Sciences Faculty
Ken Bell, Corporate Controller
Phil Heuchert, Manager Trust & Research Accounts

September 19, 1997

APPENDIX B

Primary Study: Consent Form

CONSENT FORM

The Experience of Respite during Home-Based Family Caregiving For Persons with Advanced Cancer

This consent form, a copy of which has been given to you, is only a part of the process of informed consent. It should give you the basic idea of what the research project is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

The study is being conducted by Dr. Vicki Strang and Dr. Priscilla Koop from the Faculty of Nursing at the University of Alberta.

Background Information

Family members provide care for cancer patients when they are at home. This care is very important for people who have cancer and for their loved ones.

Purpose of Study

This study looks at what it is like to care for a family member who has cancer and is at home. It also looks at how the experience of caring for a family member with cancer affects caregivers after their loved one has died.

Study Design

We understand that your home care nurse has talked about this study with you. We also understand that you are interested in hearing more about this study. You do not have to take part in this study. If you decide to take part in this study, you will be asked some questions about what it was like to care for your family member with cancer. This will take about an hour and a half for each interview. You will be interviewed twice. You do not have to answer any question if it upsets or bothers you. If you feel tired and wish to stop answering questions or you want to continue at a different time, that is fine. Just tell the research nurse that you want to stop and she will do so. Also, you can receive answers to any questions about the study at any time.

Risks and Benefits

Answering some questions could make you feel sad about your family member's illness. Other than that, there are no known risks involved in taking part in the study. Taking part in this study may be of no personal benefit to you. However, it is hoped that support for family caregivers can be improved in the long-term, based on the results of this study.

Initials _____

Confidentiality

All data from this study will be stored in a locked filing cabinet. The consent form will be kept for at least five years. The raw data will be kept for at least seven years. Consent forms and raw data will be stored separately to protect your identity. Data from this study may be used for future analysis without obtaining further consent from you. However, each study arising as a result of information obtained in this study will be submitted for ethics approval.

Only the research nurse and Dr. Vicki Strang and Dr. Priscilla Koop will know your identity. The information you provide will be confidential because names will not be included on the questionnaire. Results from the study may be published but you will not be identified in any report.

Understanding of Participants

My signature on this form indicates that I have understood to my satisfaction the information regarding my participation in the research project, and agree to participate as a subject. In no way does this waive my legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities.

I am free to withdraw from the study at any time. My continued participation will be as informed as my initial consent, so I am free to ask for clarification or new information throughout my participation.

I understand that *Vicki Strang* at *492-6333* or *Priscilla M. Koop* at *492-2962* will answer any questions that I have about the research project.

A copy of this consent form will be given to me to keep for my records and future reference.

I agree to participate in this study.

_____	_____
Name of Participant	Signature of Participant
_____	_____
Name of Witness	Signature of Witness
_____	_____
Name of Investigator	Signature of Investigator

_____

Date

APPENDIX C

Primary study: Interview Guide

Interview Guide

Demographics

Gender: Male _____ Female _____

Year of Birth: _____

What is your relationship to the family member who died of cancer (spouse, adult child, other)?

_____

What is the highest level of education you achieved?

_____

How long were you the primary caregiver to your family member who has died?

_____

Do you have any health problems? _____

If yes, please describe _____

_____

_____

_____

How long has it been since your family member died? _____

Caregiver Semi-Structured Interview Guide

What was it like to care for a family member who was dying with advanced cancer?

1. How did you manage to cope with it?
2. What part of your caregiving experience was the most stressful?
3. What part of it was the least stressful or rewarding?
4. What did you find helpful in this experience?
5. What did you find unhelpful in this experience?
6. What gave you relief from your caregiving?
7. Tell me how did it feel when you were getting this relief? What did it mean to you?
8. Describe for me how you went about getting this relief?
9. How important was it to you to get some relief from your caregiving activities?
10. Now that your family member is gone, how do feel you are doing in coping with the loss?
11. Tell me whether you feel your caregiving experience while your family member was dying is influencing your grief now?
12. Has that caregiving experience has made it easier or more difficult for you now?
13. Is there anything else you would like to tell me?
14. Thank you for taking the time to share your thoughts and feelings about your experiences with me in this research study.

APPENDIX D

Secondary Study: Ethics Approval

Health Research Ethics Board biomedical research health research

UNIVERSITY OF ALBERTA HEALTH SCIENCES FACULTIES,
CAPITAL HEALTH AUTHORITY, AND CARITAS HEALTH GROUP

HEALTH RESEARCH ETHICS APPROVAL

Date:	July 2002
Name of Applicant:	Ms. Tasnim Hirani
Organization:	University of Alberta
Department:	Faculty of Nursing
Project Title:	**Caregiver Experiences During Home-Based Palliative Cancer Care**

The Health Research Ethics Board (HREB) has reviewed the protocol for this project and found it to be acceptable within the limitations of human experimentation. The HREB has also reviewed and approved the subject information letter and consent form, if applicable.

The approval for the study as presented is valid for one year. It may be extended following completion of the yearly report form, which will be sent to you in your renewal month. Any proposed changes to the study must be submitted to the Health Research Ethics Board for approval. Written notification must be sent to the HREB when the project is complete or terminated.

Dr. Sharon Warren
Chair of the Health Research Ethics Board
(B: Health Research)

File number: B-020801-NSG

APPENDIX E

Secondary Study: Agreement Contract

Agreement between:

Tasnim Hirani, Registered Nurse

- and -

Dr. Victoria Strang, Associate Professor

Recital

Because Tasnim Hirani ("Hirani") is a candidate for a Master of Nursing degree; and **because** in partial fulfillment of this degree Hirani will be writing a thesis on Informal caregiver experiences during home based palliative cancer care; and **because** Victoria Strang ("Strang") is an Associate Professor of Nursing; and **because** Strang has obtained research data useful specifically for the completion of Hirani's thesis in partial fulfillment of Hirani's Master of Nursing degree; the parties agree as follows:

Terms

1. Hirani will have access to the data from Strang's study "The Experience of Respite During Home-Based Family Caregiving for Persons with Advanced Cancer" (P. Koop, Co-Investigator). The data will be limited to 29 audio tapes and transcripts of interviews done with the caregivers of persons who died of advanced cancer, demographic data of the same caregivers and field notes from this study.

2. Strang will provide Hirani with the use of a computer, printer, printer cartridges and computer paper for the duration of Hirani's study.

3. Hirani will provide Strang with one copy of Hirani's analytic memos, coding schemes, and field notes within a reasonable time after completion. Strang agrees to acknowledge Hirani in future use of said material.

4. Hirani agrees to submit one article for publication on the findings of Hirani's study within 24 months after Hirani's final thesis defense. The article will have Hirani listed as first author and Strang listed as second author.

5. If Hirani fails to submit said article for publishing with 24 months after Hirani's final thesis defense, Strang is permitted to submit an article with similar content, having Strang as first author and Hirani as second author.

6. Hirani agrees to acknowledge Strang in future publications or presentations related to Hirani's study.

7. Strang agrees to acknowledge Hirani in future publications or presentations related to Hirani's study.

8. Hirani agrees to acknowledge funding received by Strang for Strang's study "The Experience of Respite During Home-Based Family Caregiving for Persons with Advanced Cancer" from the Edna Marie Minton Endowment Fund and Faculty of Nursing in presentations and publications of Hirani's study.

In witness of this agreement the parties have affixed their signatures below:

Tasnim Hirani

Signed at Edmonton AB, this 12 day of [illegible], 2001

Witness

Victoria Strang

Signed at Edmonton AB, this 12 day of [illegible], 2001

Witness